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Hispanic cultural issues related to pediatric occupational therapy

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Abstract

Hispanic Cultural Issues Related to

Pediatric Occupational Therapy

By Elsy Arcila-Wilkins

This cultural inquiry involved interviewing five families from Central and South America who are raising a mentally or physically disabled son or daughter in the United States (U.S.).

This study presents information about experiences, every day life, feelings toward their children with disabilities, and coping mechanisms of the parents who were participants in the study. The parents' perceptions and opinions about occupational therapy, occupational therapists, and the medical care system are described, as well as the families' value systems and old beliefs. An analysis of professional implications based on the occupational performance frame of reference is presented. While it may be difficult to capture the richness of any culture and the many facets of any ethnic group from separate case studies, studying Hispanic families can help to enlighten those who are responsible for their care. This study brings forth facets of the Hispanic culture which can contribute to better communication between health professionals and Hispanic clients.

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CHAPTER 1

INTRODUCTION

Purpose of Study

The purpose of this study was to explore cultural issues relevant to the provision of occupational therapy services to Central and South American Hispanic parents who are raising children with disabilities in the United States. These cultural issues were studied by inquiring about the parents' and children's daily life. This inquiry revealed their viewpoints; values, norms, feelings customs, and skills that are pertinent to them relative to the disability and the services provided by the occupational therapy professional.

Statement of the Problem

Fast demographic growth of the Central and South American Hispanic population in the United States provides a challenge to the health care professional. In addition there has been little research conducted from their personal perspective, as well as scarce research that acknowledges intracultural variability among Hispanics.

Research Questions

The researcher sought answers to the following questions:

1. What do Central and South American Hispanic parents and children

value in relation to occupational function?

2. What impressions and opinions do Hispanic parents and children express about referral, assessment, and practice of services relative to occupational therapy?

3. What are some of the cultural norms and customs that compliment or interfere with occupational therapy goals?

Definitions

Definitions of terms used in this study are:

Acculturation: the process of becoming adapted to a new or different culture with more or less advanced patterns. The mutual influence of different cultures in close contact

Assessment: the overall process of determining the need for treatment. "Assessment data should include details about the individual's deficits and should always reflect the environmental context in which the individual typically performs the activities, tasks, and roles of daily living. Information on the patient's past performance and environmental demands are relevant and should provide a sense of the patient's interests, values, and use of time" (Christiansen & Baum, 1991, p. 33).

Beliefs: the state of believing; conviction or acceptance that certain things are true, or real. An opinion, expectation, judgment.

Culture: "refers to the values, beliefs, customs, and behaviors that are passed on from one generation to the next. Culture affects performance in many ways, including prescribing norms for the use of time and space, influencing beliefs regarding the importance of various tasks, and transmitting attitudes and values regarding work and play" (Altman & Chelmers, 1980; Hall, 1983).

Cultural norms: standards of conduct that should be followed: A way of behaving typical of a certain group.

Customs: usual practices or habitual ways of behaving. Social conventions carried on by tradition and enforced by social disapproval.

Ethnic: population or subgroup having a common cultural heritage, as distinguished by customs, characteristics, language, common history.

Hispanic children: for the purpose of this study, Hispanic children will be those children, either born in Central or South America, or those children born in the US., who belong to the first generation of offspring of a Central or South American family, and are being raised in the U.S.

Hispanic parents: parents who were born in any of the Central or South American Countries; and for the purpose of this study, parents living and raising children in the U.S.

Occupational function: the performance of activities related to work, education,

self-care, leisure and recreation.

Occupational therapy goals: set of standards appropriate to the individual's condition; these standards give direction to expected short- and long-term efforts during and after occupational therapy.

Practice of service: the way or manner by which the occupational therapist uses and applies her/his knowledge to treat the clients.

Referral: directed to another person, service or agency.

Values: the social principle, goals, or standards held or accepted by an individual, class, society.

Assumptions

The researcher made the following assumptions:

1. Occupational therapy makes a valuable contribution to the health care field and to all populations that seek health care services and that all members of any population and cultural group, as well as all therapists will benefit from knowing the values and beliefs that impact therapy.
2. Most occupational therapists have a limited view of the Hispanic culture and this view may be applied to all the Central and South American Hispanics, undifferentiating and disregarding ethnicity and acculturation.
3. Occupational therapists want to provide a comprehensive and meaningful service to all groups encountered in practice and benefit by becoming

knowledgeable in as many different values and customs of other cultures as possible, especially the Hispanic.

4. Hispanic parents would be interested in sharing their experience of raising children who have disabilities.

5. A Hispanic background and language fluency in Spanish would be assets to successfully understand and interpret the parents' information.

Limitations

A case study of five families can not provide data that can be generalized to the rest of the Central and South-American Hispanics, but makes a qualitative contribution in the inquiry of cultural characteristics of the Hispanic from Central and South America.

Significance of the Study

The significance of this research lies first in a commitment to the mind-body-environment interrelationship promoted by West (1984) to reaffirm traditional philosophical and practice modes in occupational therapy; second, a commitment to study individuals within the context of their cultural roles (Llorens, 1976); and third, a commitment of the author of this study to view the family in its role at the center of the child's treatment process.

The occupational therapist who has a clear and broad knowledge of the values, norms, and customs of the client and the client's family can choose from a

greater pool of resources to address the skills and performance components. All of the areas addressed in occupational therapy: self-care, work, play, leisure activities; motor, sensory-integrative, cognitive, and psycho-social functioning are directly related to the client's environment. Excluding the cultural values and norms that are part of the client's environment narrows the therapist's choices and hinders the possibilities for an optimal outcome.

The intent of this research was to initiate inquiry and provide information that enables the occupational therapist and other health care professionals to consider their role in research, and that can ultimately lead to providing better health care to the Hispanic community.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

The review of the literature comprised three areas. The frames of reference used to structure this research within occupational therapy theory and practice are occupational performance and facilitating growth and development. Review of occupational therapy literature that is relevant to the Hispanic culture and literature on similar issues in other health fields is covered.

Occupational Performance

Occupational performance as a frame of reference is illustrated in Figure 1. This frame of reference was outlined by The American Occupational Therapy Association in 1973 to specify the areas of concern and expertise of the occupational therapist. This conceptual framework facilitated the collection, and analysis of data in areas addressed by the occupational therapist.

These concerns are divided in two major areas: the occupational performance skills and the occupational performance components. Under the occupational performance skills 3 activity areas are considered: self-care, work, and leisure/education activities. Under the occupational performance components five areas of functioning are evaluated: motor, sensory/integrative, cognitive,

psychological and social functioning. The occupational performance framework provides guidelines to organize screening, evaluation and treatment in occupational therapy clinical practice (Pedretti & Pasquinelli, 1990).

Facilitating Growth and Development

Complimenting the performance skills and components proposed by the occupational performance frame of reference is that provided by the conceptualization of "successful performance" proposed by Llorens (1976) in facilitating growth and development theory. "Successful performance in self-care/self-maintenance, work/education, play/leisure, and rest/relaxation is demanded by the environment, consistent with cultural requirements at specific ages and stages across the life span" (p. 47).

Llorens (1984) explained the developmental stages and occupational performance skills based on roles comprised of expectations and adaptive behaviors. She viewed the individual as a separate, yet interactive and first level environment influenced by sociocultural roles in the family system and the community. All of the environmental levels with their specific and interactive roles must be in harmonious balance for the individual to adapt. The role of the occupational therapist is then, to facilitate and enhance the quality of role performance, and enrich the quality of his patients' lives. Structure provided by these concepts aid in the recognition and analysis of sociocultural, behavioral and

cultural requirements consistent with the patient/therapist relationship.

These two frames of reference organize knowledge-principles and statements that guide occupational therapy research and practice, and may be used to analyze theories of other professions and disciplines.

Relevant Occupational Therapy Literature

There was no research found in the occupational therapy field that specifically addressed the Central or South American Hispanic cultural values and norms from the parents' perspective. Iannone (1987) investigated the concept of occupational role from a cross-cultural perspective; and described the occupational role of a physically disabled South American from an adolescent female point of view. She compared the significance of individualism, self-reliance and independence valued in the Anglo-American culture, versus interdependence and commitment to the family, valued in the Hispanic culture.

Some of the occupational therapy literature about Hispanics does not show documentation of the source of the beliefs mentioned, the social circumstances, the statistical data that support or supported such beliefs, or the relevancy to the present. Hence an outdated, narrow, incomplete, generalized and static picture of the Hispanic Central and South American culture is still prevalent. Several examples of such beliefs can be read in the "Special Issue on Cultural Diversity" by Thompson-Rangel, published by AOTA on March 1992.

Pratt (1989) viewed occupational therapy for children as an applied health entity with a complex scope and delivery of services; and stated that one of the goals of intervention is "collaboration." This implies communication and cooperation not only with the child but also with the child's family and other meaningful people and services.

According to Moersch (1989), the first occupational therapist to prompt inclusion of the parents and to promote her suggestions as an art and as a philosophy, was Knickerbocker in 1965. Many of her suggestions prevail and guide present approach to include parents' values and family involvement. The suggestions considered are:

> Ask for suggestions from parents; recognize the value of parents' contributions; do not isolate the child; build on parents' strengths; direct actions toward maintaining a cohesive family unit; make sure that parents know why as well as how to carry out their child's program; help parents develop appropriate perspectives of the capabilities and deficiencies of their child; and structure the therapy program with the goal of developing more effective parent-child relationships (Moersch, 1989, p. 132).

Parent and family involvement, especially in home programs, impart multiple benefits to the therapist. It can make it easier for the therapist to

develop home programs, to visit and make accurate evaluations of the child's home, to explain treatment plans, to write objectives in areas of the child's strengths and weaknesses, to answer parent's questions and provide emotional support when needed, to engage the parents in frequent problem-solving, to monitor the implementation, to be able to vary activities and maintain interest, and finally, to write new objectives when new needs arise (Moersch, 1989)

Anderson and Hinojosa (1984) provided literature evidence and examples of partnership with parents. Their original conclusion was expressed very clearly, when they stated that, the time the therapist spend with the parent may be more significant then time spend with the child.

Parenting of developmentally and learning disabled children can be physically demanding and emotionally exhausting, and any program designed to meet only the child needs is not complete. Parent-child interaction is reciprocal in nature and must work as a unit in conjunction with crisis intervention principles during the therapeutic process. Parents of disabled children deal with a multitude of feelings: feelings of inadequacy, guilt, anxiety, frustration, helplessness, denial, anger, bargaining, sorrow. The final and healing stage, acceptance of grief, may never occur unless the child dies. Additionally, shock and bewilderment may be common among parents whose children's disabilities are not visible; anger and self-blame may persist and may prompt the family to seek unnecessary services

(Anderson & Hinojosa, 1983).

The occupational therapist's relationship with the parents may focus on discussion of feelings about their child's disabling condition in any of the stages of the grief process, carefully looking out for signs of parental distress such as inconsistent attendance for therapy, non-compliance with treatment, rejection of the child, and anger with themselves, with the therapist or with the facility. Therapists in turn may respond with antagonism and anger. Parents will sense conscious or unconscious messages which in turn will reinforce their inadequacy or insecurity (Anderson & Hinojosa, 1984).

The richness of the aforementioned relationship with the parents of a disabled child and with the child will depend a great deal on the therapist knowledge of cultural health beliefs, family structure, social support, and degree of acculturation. The difficulty and challenge presented to therapists of the United States is the inability of recent immigrants to speak the English language coupled, with the therapist's inability to speak the immigrant's language.

Cultural Issues in Various Health Fields

In all health fields there is concurrent mentioning of the need to address cultural issues. For example The National Association of Social Work (NASW) code of ethics urges social workers to make sure that resources and services be more accessible and relevant to different cultural groups to promote clients' self-

determination and autonomy with the extra benefit of gaining clients' trust (Congress & Lyons, 1992). In the journal Culture, Medicine and Psychiatry recent articles address issues and difficulties that Spanish Speaking patients and doctors encounter when seeking and providing medical services (Erzinger, 1991). The Society for Research in Child Development promotes and examines cross-cultural and cross-ethnic research to inform researchers about mainstream developmental issues, especially in the areas of socialization and family processes. (Knight, Tein, Shell, & Roosa, 1992).

"Hispanic Health in the United States" (1991) was published by The Journal of the American Medical Association. It was a series of articles from the Eisenhower Center for the Conservation of Human Resources, The Council on Scientific Affairs and from The Office of the Surgeon General which was published in a great effort to educate all health professionals and to stimulate coherent research on an array of health issues and problems experienced by the Hispanic population.

Five precautionary standards for counselors in the practice of rehabilitation of Hispanic clients are exposed in an outstanding article in the Journal of Rehabilitation, "Cultural Issues in the Rehabilitation of Hispanics" by Smart and Smart (1992). Research can strengthen these authors' implications and recommendations for rehabilitation practice by providing cultural and

ethnographic information representative of the people of South-American culture.

Some previous literature and research have perpetuated outdated views of the Hispanic culture; and such views at present sustain invalid stereotypes. Most of the time, cultural values are given outside of contextual significance to socio-economic situations, and norms and customs are just simply compared to a different cultural group undermining the significance of such beliefs to the Hispanic culture. In comparison to the lack of research of the Central and South American Hispanic, there exists an abundance of research on the Mexican group and a marked tendency to extrapolate and generalize those findings to the other Hispanic groups living in the United States, groups who have had different immigration patterns, labor market conditions, and lifestyles (Smart & Smart, 1992).

The Census Bureau, in its current population surveys, uses two categories to designate the Hispanic composition of the U.S. population: 1)The "Other Hispanic" group composed of people whose ancestry is directly connected to Spain, Spanish settlers in the U.S. southwest and any individual of mixed Hispanic heritage and cultural identification; and 2) The group that is composed of the "Central and South American Hispanic" (The Hispanic Almanac, 1990)

Before the 1980s the Central and South American population in the US was very small and mostly comprised of legal immigrants. Political and economic

unrest in many of these countries during the 80's prompted many South and Central Americans to seek employment, and practice professional training of skills that are not sufficiently compensated in those countries. This group has experienced the highest rate of growth since 1982, with a 67% growth rate, increasing from 1.5 million to 2.5 in 1989. This concentration occurs mainly in border states and historical immigration entry points: California, Texas, New York, Florida and Illinois (The Hispanic Almanac, 1990).

A noteworthy reference Cultural Diversity in Health and Illness (Spector, 1985) provides information to sensitize the reader and student to diverse cultural issues. Her second concern is in reference to acceptance and deliverance of health care and associated pragmatic problems. Two comprehensive tables, one on familial folk remedies and the other on beliefs that can affect therapy based on ancient and modern forms of healing are presented to illustrate an overview of beliefs and customs of various ethnic and religious backgrounds in this country.

In the same book, Spector (1985) pointed out that addressing poverty is part of most ethnographic research, explaining that poverty is an obstruction in the delivery and acquisition of health care. The provision of health care services is directly connected to economic factors; and identifying this and other barriers is important in accessing the system, because some of these problems are directly related to belonging to an ethnic group different from the prevalent ethnic

majority. The last portion of the book presents a moderate exposition of traditional health and illness beliefs of the following subcultural groups in the United States: the Asian-American, the Black-American, the Native-American and the Hispanic-American; and without deviating from research tradition, provides insight only into the Mexican-American and Puerto Rican subculture.

The American Nurses' Association has tried to sensitize health care professionals to the cultural issues of diverse client populations in the U.S. for many decades. This is evident in the journal articles, and books written about the subject. Transcultural Health Care by Henderson and Primeaux (1981) present an exploration of the sociocultural dimensions of health care, folk medicine, and patient care with an impressive list of contributors in the subjects mentioned. A separate analysis of this book, will be included here because several of these themes appear in many of the health articles reviewed.

Transcultural Health and Cultural Diversity

The majority of Americans can claim ancestry to some other country and may feel proud that their culture at some point in history has enriched today's American culture with their values, customs, music and food. Recent immigrants and their American born children, or first generation, practice and teach their cultural characteristics to their succeeding third and fourth generations. Thus, eventually, ethnic characteristics start to blend with the American culture

acquiring common elements and basic beliefs. This is readily manifested in the disappearance of stereotypical masculine and feminine roles, along with other characteristics of their grandparents' culture (Henderson & Primeaux, 1981).

In spite of this explanation, Henderson and Primeaux (1981) stated: "Some ethnic groups-mainly those of color-never achieve assimilation" (p. 8). What do the authors imply here by assimilation? Do they imply that some ethnic groups, especially those who have brown and black skin color are not accepted by those who have light skin color? Or do they use the term "assimilation" as a synonym for acceptance? Another statement from their book read, "The assimilation of the more recent immigrant groups seems to be unlikely; most of them are of the lower socioeconomic classes, and they tend to maintain their traditional beliefs, attitudes and behaviors" (p. 9); and "Most bilingual bicultural subcultures have not assimilated into the American Melting pot because they prefer not to assimilate" (p. 13).

Numerous research studies have documented the difficulty that children of immigrants face because their educational and occupational success is greatly determined by their parent's social class. Social class affiliation is a strong determinant for educational level and occupational performance. Then it is crucial to keep in mind that social class can be a stronger determinant of behavior than the ethnic background. Equally unsettling for the health professional, when

working with a member of his own ethnic background, is the realization that, he or she can appear condescending, at one extreme, or estranged and uncomfortable, at the other (Henderson & Primeaux, 1981).

Sophier (1981) in "Gaining Awareness of Cultural Differences" relates her experience of when for a year and a half she had the opportunity to become immersed in the Jewish culture while providing care for an elderly Belgian Jew. She alluded to this event as one of her most rewarding nursing experience and the deciding point in her life that prompted her to focus on transcultural nursing. She maintains that it is not necessary to "go native" or immerse oneself in a different culture to provide sensitive health care, but that it is necessary to want to protect the rights of the patient while acknowledging cultural differences. Cultural immersion or at the least cultural awareness enables the health care provider, in time, to differentiate between physical pain and anguish, and when medication does not alleviate the pain, listening with empathy makes a profound difference. Uninvolved involvement that health care practitioners are taught to exercise is more challenging in a bicultural situation because the practitioner needs to learn new cultural beliefs where more personal involvement.

Important contributions to the cultural analysis of the Hispanic have been made by Hall in The Silent Language (1959), The Dance of Life (1983), and

Understanding Cultural Differences (1990). Among some of his contributions are his explanations about the use of time and space and his definition of culture shock. Hall defined "culture shock" as the "removal or distortion of many familiar cues one encounter at home and the substitution for them with other cues which are strange" (p. 199).

Hall (1983) categorized polychronic and monochronic time and observed that some cultural groups adhere more to one or the other time schedule. He defined polychronic time as time used to do more than one thing at a time and oriented to promoting human interaction and relationships; and monochronic time as time characterized by tasks, schedules and procedure. Hall claimed that the Hispanic adheres to polychronic time.

Language

The way ethnicity compounds the challenge to health care professionals is magnified by the language barrier of immigrants. Marcos, Urcuyo, Kesselman, and Alpert (1981) claim that when psychiatric evaluation interviews are given to bilingual Hispanic patients, more pathology is found when the interviews are conducted in English, even when content and presentation variables were maintained identical. The case in point involved ten patients being admitted at a Psychiatric hospital; their ages ranged from 21 to 42, the average number of school years was 8.7; and their average number of years in the U.S. was 18 years.

Greater pathology was found based on the following: 1) The patients gave different responses to the same questions in English and Spanish; 2) The English answers where shorter, a single word, or no response; 3) There was a remarkable difficulty in using the past tense; 4) "Language mixing" was used frequently; 5) Increased speech rate in English was evident when anxiety increased, and higher speech rate in Spanish was evident when anxiety decreased. The results of this study yielded information that while these patients were using the English language, their flow of thought appeared less logical, and the patients' responses appeared irrelevant, more concise and formal. The patients were seen to have flat affect, to be less fluent, less communicative, and more incoherent, uncooperative and disorganized. In contrast, these characteristics were either absent or minimal when using the Spanish language.

In addition to language issues, a commonalty found in the literature addressing the Hispanic culture in books and academic journals was the exposition and analysis of folk health beliefs. In an effort to discover the original source of this information, the researcher of this thesis found George M. Foster's work. Foster, a medical anthropologist whose field research and data on the Hispanic culture extends from the 1950s to the present will be discussed under the folk medicine and medical anthropology sections of this review. In 1953, Foster published "Relationships Between Spanish and Spanish-American Folk Medicine"

in the Journal of the American Folklore. In 1978, Foster and Anderson in the book titled Medical Anthropology modified, refuted and updated the information of previous studies. However, in 1981, Henderson and Primeaux reprinted Foster's 1953 article and many authors began citing this information which was updated in 1978.

Folk Medicine

Foster's 1950's study, reproduced in the book titled Transcultural Health Care, and published in 1981, explained that Spanish and Spanish-American Folk medicine represented the accumulation of classical Greek and Roman, as well as indigenous doctrines and practices. Among significant contributors are the Pre-Christian and Christian, Pre-Arab and Arab, Mediterranean and Mores. Important authorities from the classic and Arabic periods were Hippocrates, Galen and Avicena. Through the Spanish travelers to the new world, the indigenous pharmacopoeia became incorporated with contemporary medical and folk practices of Spain.

Foster's 1950's anthropological study and field research of Spanish folk medicine included the study of ancient health beliefs and conditions of: "susto" or stress, "mal aire" or bad air, "mal ojo" or evil eye, "empacho" or indigestion, "caida de mollera" or fallen fontanels. Some of the general curing techniques included: nine-day treatment, "al sereno" or in the open air at night, "en ayunas" or before

breakfast, hagiolotry or worship of the patron saints, the "perpicaz," "saludador" or "curandero," and herb specialists or naturalists. According to the Foster study, one remarkable characteristic of Spanish-American folk medicine is implicit acknowledgement that many emotional experiences are the cause of illness and disease and "not natural," supernatural or witchcraft, contrary to the old world belief that the individual fell victim to natural and supernatural causes, witchcraft and bad luck. More specifically, evidence gathered then suggested that there existed more Spanish folk medicine in Peru and Chile than other southern American countries.

How vigorous is folk medicine now, and does it play a functional part in the every day lives of the people of South American origin living in the United States? These facts remain to be determined and validated by research. Foster's 1950's inquiry and study of Spanish and Spanish-American folk medicine is one of the most complete descriptions of health beliefs, coupled with relevant historical background.

Mentioning the beliefs stated in Foster's study is a common practice and they appear in several succeeding culture and health care books and journal articles. Foster's great contribution to anthropology, especially medical anthropology is greatly appreciated; however, health care researchers must take into account the period from which this and similar research comes, which is the

1950's and before, and also, researchers need to take into account the specific population that was used to exemplify these findings. After the 1950s when the communication explosion and great urbanization took place (Winn, 1992), many of these beliefs may not have endured, and the researcher is left with the question, did folk medicine resist the inroads of modern medical science?

Medical Anthropology

Foster and Anderson (1978) based their work on many medical anthropological studies and updated the literature about the trends in anthropology and medicine in a changing world. Foster and Anderson not only explained how scientific medicine has taken a strong hold, and traditional medicine in spite of being effective in some areas, lost some of its role, but they also gave numerous examples of how believers of traditional medicine have shown great ingenuity in integrating scientific modern medical practices with their personal belief systems. Even though this and similar updated information has been provided, there has continued to be persistent referencing of outdated beliefs in health articles along with pleas for health professionals to learn these beliefs and keep them in mind when relating to Hispanic patients and clients.

However, is it really useful for the health practitioner to learn about health beliefs that had been described because they provide an out of the ordinary, exotic or bizarre ritual? Are these beliefs practiced by people who lived predominantly

in rural areas and therefore held by a few? To answer these questions it is useful to keep in mind the Foster and Anderson (1978) statement "anthropologists historically have studied the 'underdog' of the world, powerless peasant communities and small tribes" (p. 167).

Similar questions and conclusions can be formulated and drawn when reading the articles "Conceptions of health and disease among Spanish-Americans," and "Some health beliefs of the Spanish speaking" in the book titled Hispanic Culture and Health Care edited by Martinez (1978). The word Spanish-American is used to refer to the descendants of Spanish inhabitants that populated the southwestern part of the United States. If researchers read the footnote in fine print, on the first page, they can see that these studies were explorations of beliefs in a particular population, place and time, and do not apply to the entire Hispanic culture; and therefore will be inaccurate to apply the general conclusions to the different Hispanic groups living in the U.S.

Three revealing insights appeared after reading most articles about health beliefs of the Hispanic. First, the titles of some of the chapters imply that the content applies to all of the Hispanic population, when in reality the topic is related to one or two subgroups of that population. Secondly, when the knowledge of one scientist is referenced by succeeding researchers, and one category or variable is isolated for testing on a specific subgroup, then after

studying the specific variable and subgroup, the conclusions do not apply to the entire group. Third, some researchers who have referenced secondary sources without regard to limits and disclaimers have perpetuated a single view of a topic and disregarded the limits and disclaimers that were provided in the primary source. In all fairness, one may add that these are the difficulties encountered in ethnographic research and any confirmation of previous research builds knowledge, but the persistent practice of referencing archaic information will build amusing but obsolete knowledge.

Miller, Drayton and Lyon (1979), in reference to medical treatment preferences, affirmed that before 1900 the use of folk remedies was common in tradition and in practice in rural America, but that this is no longer so for North and South America. Most urban dwellers reject such cures and seek modern techniques and licensed physicians with the resulting disappearance of a vast majority of beliefs and practices. At present, how relevant are these health beliefs, and to what extent they influence the decision to seek modern medical care in the Central and South American Hispanic population in the U.S.?

Summary of Literature Review

Two frames of reference, the occupational performance and facilitating growth and development, are defined and analyzed in this literature review to guide and relate this research to the occupational therapy profession. Review of

occupational therapy literature and various health fields revealed an emphasis on outdated folkloric health beliefs, usually extracted from numerous studies about the Mexican-American and the Puerto Rican-American Hispanic.

General themes of the Hispanic cultural values, as well as common themes addressed in academic health literature were examined. It was found that there was a lack of differentiation between the Hispanic's beliefs of pre-1950's rural remote areas, and the cosmopolitan Hispanic of the 80's and 90's. It was common to find references that occurred in previous writings of cases studied more than 30 and 40 years ago, while referencing of more recent findings is not common. A commonality found in most of the literature was the plea for addressing cultural issues in academia and in professional practice; yet a more accurate plea would be to update knowledge of the Hispanic culture through contemporary research.

CHAPTER 3

RESEARCH METHODOLOGY

Qualitative case study methodology was employed in this study and data were collected through recorded, in-depth interviews with the intention to inquire how five Hispanic families live and cope with their new environment and with their children's disability.

Questions

This study was designed to answer the following questions: 1. What do Central and South American Hispanic parents and children value in relation to occupational function? 2. What impressions and opinions do Hispanic parents and children express about referral, assessment, and practice of services relative to occupational therapy? and 3. What are some of the cultural norms and customs that compliment or interfere with occupational therapy goals?

Subjects

The participants in this study were five Hispanic Central or South American families with children who are receiving occupational therapy services through school districts, state or county offices, or other pediatric occupational therapy services in California and Colorado. Four of the interviews took place in the subject's home and one at a public place. Most of the children were present.

Participants were chosen regardless of race, mixture of races, acculturation or integration into the American culture. All of the five families were of Hispanic Central or South American descent and cultural background. Their socio-economic stratum varied. Based on their income, three of the families belong to the lower-middle class and two to the middle class. The number of persons interviewed was seven, two couples and three women. Each of these families had a child with physical and mental disabilities and were receiving occupational therapy. All the parents interviewed were born in Central or South America and came from urban areas. Four of the children were born in the U.S. and one was born in South America.

These families were willing to share their knowledge and were interested in developing a collaborative relationship. They were guaranteed appropriate protection from risk, as well as anonymity of their identity and data collected.

Instrument

The Arcila-Wilkins Cultural Questionnaire (A-WCQ) was created for this study by the researcher (see Appendix A). This is a three part questionnaire comprised of informal and flexible questions. The first part asked questions relevant to every day life style and activities. The second section of questions was about the child's disability and occupational therapy. The last section of questions asked for confirmation or denial of old beliefs found in the literature or heard by

the researcher.

Ideas for questions to create the informal interview questionnaire came from reviewing a "Cross cultural questionnaire" used in "Health Professions in a Multicultural Community" class taught by Professor Guy McCormack, Ph.C., O.T.R. at San Jose State University in 1992 and from Working with Families: A Curriculum Guide for Pediatric Occupational Therapists by Hanft, et al. (1992). Some of the items related to old beliefs came from an article titled "The Hispanic Child and Family: Developmental Disabilities and Occupational Therapy Intervention" by Thompson-Rangel (1991). Other beliefs were taken from academic articles found during the literature review. And finally, additional questions to address common knowledge of the Hispanic South American culture were added to the questionnaire based on the researcher's experience.

Procedure

Three large school districts in the San Francisco Bay Area were contacted by phone, mail and in person to secure subjects to interview. One school district after having granted permission to contact the occupational therapy department, retracted. Two reasons given were confidentiality (even though I was guaranteeing absolute confidentiality) and that the school district was going through some type of litigation and school district authorities were being cautious. The second school district responded that of all their 125 cases, they did not have

a single Hispanic family in their case load. The third district provided a few names and one of those families was chosen.

Many calls were made to occupational therapists working in pediatrics in California and Colorado to secure other parents for the interviews. Many helpful therapists were found in both states. In addition, the Occupational Therapy Association of Colorado distinguished itself for their strong therapists' network and the generous and helpful information provided by each therapist contacted. After receiving leads, several calls were made to each of the prospective interviewees. In a couple of cases, even though the parents had agreed to be interviewed, they found it very difficult to keep the appointment. The most common reason given was the inability to find an appropriate time that would not interfere with the family's routine.

The easiest interviews to schedule were the ones that were scheduled one or two days after initial contact. The interviews that were more difficult to schedule or that never took place were those that were scheduled for a week or more past the initial contact. In conclusion, securing the subjects was a greater difficulty than anticipated.

The data were obtained via recorded, in-depth interviews. Casual observation of parents and children took place when it was appropriate. Some of the approach used to collect and analyze the data included elements used and

suggested by Clark in the 1993 Eleanor Clarke Slagle Lecture titled "Occupational embedded in a Real Life: Interweaving Occupational Science and Occupational Therapy." Some of the elements mentioned were: to provide descriptions of actual cases, complex sets of events, and related episodes to form stories; to contextualize therapy within the person's real life; to respect subjectivity, rapport and equality; to promote meaning; and to nurture the human spirit to act.

Careful attention was paid to avoid generalization to all Hispanic groups who are not represented in this study. In order to address this area of concern, the researcher kept in mind the distinction between ethnicity and acculturation, that is, belonging to a particular race or races, and having adapted to the norms and life style of another culture.

Two frames of reference of occupational therapy were used to analyze the data, and a review of multiple and relevant chapters and journal articles was utilized to sort and analyze cultural themes. Data were also analyzed following the structure of the interview, the emergence of cultural patterns or behaviors, old beliefs, research questions and implications for the practice of occupational therapy.

CHAPTER 4

DATA AND RESULTS

Presentation of Data

Data were collected through interviews with one or both parents of the child with disabilities, during six months in 1994 in California and Colorado. Data are presented by categories used in the questionnaire: the answers to the section titled "Culture" are used to describe the "Life Style and Customs" of each family followed by the answers to the section titled "Occupational Therapy for ....." their son or daughter. All five cases are presented in this manner before presenting the data about "Old Values and Beliefs" that were gathered from all the participants. Unlike the life style and customs and occupational therapy data that are presented individually and descriptively, the data about "Old Values and Beliefs" are presented together for all the cases because these data are the result of YES or NO answers and did not require explanations during collection.

The length of the interviews varied from one and one half to three hours. All of the participants are immigrants from Central or South America and are raising children with disabilities. In four of the cases the children were born in the U.S. and in one case the child was born in South America.

In the first case interviewed both parents were present, but the father

participated more actively and answered most of the questions. In the second case, both parents were present and both actively participated in answering all the questions equally. In the third and fourth interviews the mothers were divorced, and answered all the questions. In the fifth interview, the mother provided all of the answers. The total number of interviewees was seven. This study confirmed that when gathering cultural information, under normal circumstances, there is no better source of information than the original informant.

All of the participants showed interest in discussing every day life as well as cultural beliefs and shared their insight into the condition of their child. The first case includes a detailed account of how the father really feels about his child's permanent disability. The fifth case presents a moving portrayal of how the mother felt soon after the birth of her disabled child, and her rejection of him for several months thereafter.

Case One

Life Style and Customs

The family as Case One is from urban Guatemala. The 39 year old husband has resided in the United States 24 years. His 27 year old wife has resided in the U.S. 14 years. This family has two children, a 7-1/2 year old boy who has a diagnosis of autism and a 1-1/2 year old girl who has no disability. The paternal grandmother comes from Guatemala to spend three or four months a

year with the family. The husband is a van driver who delivers and loads food onto commercial airplanes. The wife takes care of all the homemaking and child care responsibilities. The family speaks Spanish at home all of the time.

The children are taught to pick up their toys, clothes and dishes. They celebrate Christmas, the new year, and some birthdays. The husband's and wife's families visit each other and have dinner together often. Their celebrations consist of sharing food, American and Guatemalan, music and some dancing. The family and their neighbors informally invite each other to their children's birthday celebrations. The invitation takes place by telephone or in person; sending a card as invitation to a family party would be considered to be too formal.

In this family when someone is sick, a doctor is consulted. They do not consult herbalists or curanderos. Rarely do they use any procedure that is not prescribed by a doctor, and the father explained that the grandmother might use harmless herbs. He added that "once, the grandmother bathed the infant boy in rosemary water when he had a rash to refresh the child's body."

A typical day for the mother starts at about 7:00 a.m. after helping her son get dressed, dressing her daughter and serving breakfast. The mother then takes her son to the bus stop. Upon returning home she takes care of her home duties and her young daughter. At three in the afternoon she picks up her son and

spends the rest of the afternoon with her husband and children. A typical day for the husband starts at 3:00 a.m.. He arrives at the San Francisco pier at 4:30 where he starts his route toward the San Francisco airport, he works 8 or 9 hours delivering food and returns home at around 1:30 in the afternoon. He rests until their son comes home from school. They will then either work in their vegetable garden, go the park, take the dogs for a walk, go shopping, or stay home. He stated: "I think we live a very quiet life, we really don't go out a lot, but we are very close to our family and we see them often."

They stated that they make the important decisions by mutual agreement; however, when there is disagreement the husband is the one that makes the final decision. They agreed that there is little disagreement. The wife said that she is bored staying home some of the time, and when her youngest child is going to preschool she would like to go to school and learn English and clerical skills to work part time, but she wants to be at home when the children come home from school. The husband is in agreement with this and said he would support his wife in her interests.

The husband contributes all of the money needed for their expenses. The wife clarified that she would like to contribute. The husband claimed that their economic situation is better than most in the same economic class because they do spend their money wisely. He likes his job because it is stable, but he was

raised in a city and was not used to doing manual labor. His ambition was to study Business Administration, of which he completed two years. He said, that it is difficult for him to go back to school at this time because of his responsibilities, his work schedule, and because he likes to have his house in good shape. The company where he works has a school program for those who want to learn or improve their English language skills, but not for financing a new career. He added that sometimes he thinks he should prepare himself for another type of work or job in case he loses this one. In any case, he concluded by saying if he lost his job, he would find another job right away doing any thing to keep what he has.

Occupational Therapy for their Son

The child with a disability is 7 and 1/2 years old and was diagnosed as autistic at the age of 2. The parents believe their child is ahead in some areas and delayed in others. The teachers and therapists have told them that their child is very smart and has a lot of potential. Now he knows numbers, the alphabet, colors, can write his name, and the names of many objects and animals. He can speak several words, but cannot use them in phrases. He rarely speaks in sentences. He uses one phrase to mean many things, for example he says: "I want boy, I want bus, I want food." The father stated that what is most difficult with his son is to know how much is in his mind, how much he really knows.

Communication with their son must be very specific and simple, such as naming objects and not using ideas or concepts. His son can follow orders sometimes but not always. He performs some activities appropriately for his age, others he does not. There are some activities that he performs that the parents do not know whether they are appropriate for his age.

Until the child was 1 and 1/2 years old they thought their child was normal. The father explained, "neither one of us have had children and infancy masked our child's symptoms." During these first 2 years, they only questioned the fact that their child did not speak because the child's behavior was not too different from other children of his age. After the child had physical examinations, the pediatrician always said he was developing normally, and that, he did not speak yet because he did not have siblings and did not go to preschool. The mother added that she believed that her child was well behaved because he never cried when she laid him down in the crib. The father added that the baby could not tolerate being held in a horizontal position and they usually held him vertically. On occasions when the grandmother was around she would say that the child's cheeks were going to become droopy from his being held in a vertical position. "We held the baby vertically most of the time," and laughing he said "and his cheeks did not become droopy. Of course we did not believe his cheeks were going to be droopy."

At about the age of 2 and 1/2 or 3 years of age, a pediatrician asked the parents a series of questions relative to their child's developmental level, and the parents started to realize that their child was doing some things differently or not doing them as expected. With sadness on their faces they added, that they did not know if they had been causing unintentional delay. "He was our first child, and we did not know any better. When he insisted on walking on tip toe, and turning and turning standing on one spot with his hands extended, like a little airplane, we did not have a clue that this was a sign of autism, we thought it was childlike, funny and appropriate of his age." Then, the father started to talk about how he felt when he found that his son was autistic.

> I hurt a great deal, and I still feel the pain. Once, a friend made a comment implying that I could have caused my child's disability because I "partied" a lot when I was young. That comment intensified my pain and guilt, and at the same time, I thought that my friend did not think before he talked. While the testing was being conducted, which took several months, I kept hoping they were not going to be able to give me a serious or conclusive diagnosis. At the beginning I felt I was having a nightmare, I was confused and hoped that the doctors and therapists had made a mistake. Now I still feel bad. It hurts when I watch other

> boys without disabilities. Fortunately, the workshops we have attended to learn about autism have helped us a great deal to control the feelings and get rid of the guilt I felt then. I know now that there is no reason or cause known for autism. We would like to have a third child for our daughter's benefit. We want her to have a brother or sister whom she can count on for moral support, and at the same time, to relieve some of the responsibility she may feel toward her disabled brother. Economically, this is going to be difficult and if we have another child it needs to be soon, so they can be close in age and interests, and so that we can raise them close to each other. Comprehending the diagnosis and the implications, was very difficult for us at the beginning.

They stated, that they get a lot of support from their family, especially from the husband's brothers, who have never made inappropriate comments; and on the contrary, have urged both of the parents not to be too strict with the child when they are visiting. When visiting relatives with their son and he is hyperactive or mischievous, speaks loudly or screams, relatives ignore the child and are more tolerant than are the parents. The relatives ask the father to let the boy be; and they affirm that the child's behavior does not bother them. When there is

progress made in behavior, or any small achievement, the family takes notice, lets the parents know, and rejoices in the child's progress.

Nonetheless, the parents admit that their child's condition is very demanding. Sometimes they see their situation as exasperating. This occurs more often for the father, and this happens once every other month or so. The father added, "It is very difficult, but we love him immensely, and even though with all the misfortune his disability implies, we try to overcome the situation." Nowadays, they go out more often, and the father says he does not want to limit their life style as other families whom he knows have done.

In the district where the child attends school there is not a separate class for autistic children, and he is taught with children who have various other disabilities. The father stated that his son's behavior prevents him from being in a class with normal children. The father would like to see his child have the opportunity to be in classes with children who are not disabled, but the mother expressed concern because the number of children in the son's class is 10 while the classes for nondisabled children have enrollments of 28 to 30. She is uncertain of what her child's reaction would be in that type of environment because noises and crowds make him excited.

The father expressed having a fair amount of control on the desired results of his child's therapy. They have a choice to send their child to two schools in the

area and they have chosen the one that provides discipline, order and quiet in the classroom. That school is farther from their home but they believe that it is better for their son. He also stated that they have had good luck with their therapists, that they all have been very good with one exception. The exception was noted when the teacher pointed out that the therapist was not teaching the child any skills. The teacher suggested that they request another therapist, which they did. The therapist was notified and she went to work somewhere else.

"Yes, occupational therapy goals correlate with the activities in our home" the father affirmed. Something that has helped them a lot is the treatment their child has received to alleviate tactile defensiveness. "Now he comes close to us and hugs us, and lets us hug him. This has given a great deal of pleasure to all of us, and makes us forget those unbearable times." The occupational therapist also addresses equilibrium dysfunction. She uses swings, big balls, compression of the joints, massage of his arms and hands, and desensitization of the skin. The father added that one of the beauties of being a child is to play with all kinds of objects, including dirt, rocks, sand, water, and animals. He urges his wife to let the child play in the yard without constant admonition about getting dirty. To which the wife responded, "very soiled clothes are more difficult to wash, besides he is allergic to many things and gets sick easily." The husband added that she is very neat, while having some mess around does not bother him. "One thing that is

very difficult is to see our child so normal physically and yet, exhibit such different behavior."

On a couple of occasions when they had observed at school that other children with more disabilities are tied to a chair or platform, and have seen them screaming, "perhaps in pain," they have not known what to do, and have chosen not to say anything, but this, they said, is very disturbing to them. The husband says that this has really hurt him, and hopes his child is treated well at school. On another occasion the therapist brought another child to their child's therapy session and the father wanted to know why, the therapist explained that she was teaching them how to take turns, and the father was satisfied with her explanation.

Initially, it seemed strange to the parents when they took their child to be tested and the therapists used a lot of different toys and games, the parents did not know what was going on. If not for the explanations given by the therapist on the purpose for using toys and games, he said, he would have thought that it was dumb. He was concerned that his son had problems and he would not have liked to have the therapists just playing with their son. Now they like it very much when the therapist uses toys and games and they think that it would be very helpful if they were given suggestions for toys and their use to compliment the therapy at home. During therapy their son requires direction and redirection.

When he loses motivation to participate, the therapist changes activity. His favorite activity is swinging, and he loves to play with water.

The parents said that they have always thought the therapy is excellent and the therapists and teachers have expressed satisfaction because the family has always been involved and interested in their child's school work and therapy. The mother expressed a desire to observe and even help once a week or so, if she was invited to do so, and if her presence in the classroom did not cause a change of behavior in her child. She also said that it would be very helpful to receive a short update on goals on which the therapist is currently working. The therapy for their child does not require any painful procedure. If there was something that was painful they would consult the doctor and they would decide if the pain was greater than the gain, if so, it would not be worth it. But if the activity is related to discipline, and if the father could only control disruptive behavior by spanking the child, then he stated, "with sorrow, I would spank my child to make him comply." They both enforce the discipline equally, he said, "We want to make him independent, and strong and that is why we teach him to control his behavior."

On one occasion when the therapist suggested that the parents lock the child's door to keep him from coming into the parents' room every night, they thought the therapist was crazy. They were expecting her to suggest some other

approach to the problem, a more gradual and less drastic measure. Instead, they decided to lock their door, and when the child cried and insisted on coming into their room, they would take the child to his own bed, comfort him and help him to go back to sleep.

In reference to the first meeting and impression of an occupational therapist, the husband said that he was very surprised that "she liked to touch and touch him as she talked and talked." If she was a Hispanic therapist, he said, he probably would have not noticed it so much, but because she was an American woman he thought: "does she like me or what?" Later I concluded that she behaved that way because she was not only accustomed to using her hands during therapy but also because that it is the way she was, a very emotional and warm person, and she was the same with everybody. To this the wife added, "she was more so with my husband than with me" and laughed. They invited the therapist over for dinner a few times. She took pictures of their son on a regular basis, and showed him affection by hugging him and rubbing his head. Their son became very attached to her and so did the parents. She was the child's therapist for two years and they felt her departure very much. They expressed a lot of gratitude for all that she did for their son.

At the onset of therapeutic treatment, their son did not want to go to therapy and he was afraid of strangers and noises. The way the therapist coaxed

him into following her to the therapy room was by offering him popcorn. Gradually the child learned to follow her without any difficulty. During class, he sometimes showed his teacher the card that read "I want to go to the Occupational Therapist." This was the form in which he expressed his liking for occupational therapy and his therapist. The parents said that the first therapist left a wonderful and unforgettable memory, but the third is a very good therapist also. He said he does not expect that all of the therapists are going to be friendly and have time to develop a friendship, and as long as his son is being benefitted, he appreciates it just as much.

The father related something that was puzzling to him. On one occasion his son was misbehaving at the dinner table, and was out of control and seemed not to be able to stop. The child himself, took the father by the hand and laid down on the floor with his arms crossed over his chest motioning to the father to sit on top of him. The father thought this was a very strange behavior and the next day he tried to find out at school what could be occurring to get such a reaction from his child. "Is this the way being used to discipline my son?" he asked at school. "Of course, they answered me that was not the way they were disciplining my child." After that incident the child has not reacted that way any more, and the father said he was glad he had gone to express his concern at the school. He does not hesitate to ask questions if he has questions to ask; he said

he works in a English speaking environment and speaks the language well. This is not entirely the case for the wife. She said she would feel more comfortable and would not hesitate to ask the therapist questions if the therapist could speak Spanish.

To conclude the interview, the father stated that he fears some families do not get information early enough about resources available for them and their disabled children, information that can easily be transmitted through the Hispanic radio and television on a regular basis. He also believes it is very important for the therapist to explain to the parents what she is doing in therapy and why.

Case Two:

Life Style and Customs

This family is from urban Costa Rica and has lived in the United States since 1968. They speak Spanish at home all of the time. This family is composed of the 40 year old mother, the 48 year old father, two girls 10 and 8 years old, and the maternal grandmother. The father is a mechanical engineer and the mother works as a teacher's aide in special education. She is also the president/secretary of the parent's support group for families with disabled children in the area where she lives.

The husband is in charge of the major expenses, and the wife contributes with her part time salary. She is also in charge of most of the children's care and

household responsibilities. The husband's job requires him to travel about fifty percent of the time. The wife works three days a week outside her home, at her youngest child's school.

The daughters' responsibilities are to "pick up after themselves," and "to do their schoolwork and study." Three rules that the parents enforce are: 1) do not play outside of their house; 2) never to use bad language, and when they visit any one; and 3) observe the best behavior including never to touch any object without permission.

The holidays and important dates this family celebrates are: the new year, Christmas eve, Christmas day, and the children's birthdays. These celebrations are simple, and usually occur with just the immediate family which they state to be, a small and tranquil family.

When someone in the family is sick they go to the doctor or the hospital, although they believe that certain herbal teas are helpful in alleviating minor ailments "because some herbs have medicinal properties." They do not refer to herbalists or curanderos of any sort.

A typical day for the father starts at 6:30 a.m., with his leaving for work at 8:00 and doing all of his related job activities as a mechanical engineer. He returns home around 7:30 p.m. When he is traveling he works on a 12 hour schedule 6 or 7 days a week, providing the same type of service at different job

sites in other states. When he is at home during weekends, he spends most of his time in the house with the family, resting, playing with the children, reading, playing with the computer, watching television, and doing other leisure type activities.

A typical day for the mother starts at 6:30 a. m. helping her daughters get ready for school, preparing breakfast, driving them to school, then going to work where she remains until 3:00 o'clock, three days week. The days she does not stay working at the school, she runs errands and takes care of household shopping and chores. In the late afternoon she helps the children with their homework, prepares dinner, supervises their playtime; and at bedtime she reads with them and tucks them to bed. On weekends she "does a little of everything," finishes tasks than need to be finished that week, and takes the children to church. Once in a while, she takes the children to an outing with other parents and children with disabilities.

All the important decisions are taken in mutual agreement and husband and wife communicate with each other daily, even when the husband is traveling. Today, there exists the remote possibility of being laid off from work, he stated, "This is a situation that exists in most American companies, but my job or economic situation is not unstable now."

Occupational Therapy for their Daughter

Their 8 year old child is autistic and has received occupational therapy since the age of four. When she started preschool, the teacher communicated to the parents that some times their daughter did not hear when the teacher spoke to her. She suggested have their daughter's hearing checked. The parents had also noticed that she had flaccid tone. The parents had her hearing tested. The findings of this test were negative. The child was then taken for physical examinations and a battery of tests, culminating with a definite diagnosis of autism at age four.

The parents' first reaction to the diagnosis and prescription of occupational therapy was to get a dictionary to try to understand the meaning and the implications. They had a general idea of disabilities, but nothing specific in relation to autism. The diagnosis was confusing, especially when it was added that there was no cure for this condition, that the treatment consisted, primarily, of occupational and physical therapy.

The parents believed that what the occupational therapist is trying to do is to improve the physical condition of the child's muscles. The therapy that their child needs is mainly in language comprehension, breaking down instructions in steps appropriate to her level. She also needs therapy to overcome her difficulty with coordination and balance.

The mother thinks her daughter's case is very interesting. In some developmental areas she is advanced and exceeds the expected developmental level, but in others she is delayed. Once the daughter understands what is required of her, she is capable of performing very well and continues to do so independently; however, there are instances when it is very difficult to get her to understand. In other words one of her difficulties is directly related to comprehension, and often, there is a need to explain things to her a few times. She speaks well and is bilingual. At home, sometimes, she answers in English and sometimes in Spanish, but she always speaks Spanish to her grandmother. They stated that they are a very small family but very close, and really enjoy their children.

The mother continued that it was difficult for others to understand, that any child with disabilities presents a very interesting case. This is seen as a challenge that teaches parents to see life in a different light and to enjoy it in a different way. Every step forward brings a lot of joy and it is considered a family triumph. "We are a very small family and both daughters have brought a lot of joy and this is why we are together as much as possible. Our older daughter loves and helps her sister very much, and I think it is not because her sister is a special child, but because my older daughter is a helpful child by nature."

When describing the demands or hardships that their child places on them,

the mother pointed out that, teaching safety is crucial. "Safety must be taught and must be kept in mind all the time with an autistic child, for example when crossing the street, or when handling sharp objects in the kitchen, because my child does not anticipate danger." Also, the mother reiterated that they are homebodies and when they visit anyone, they are very alert to prevent any harm to the children or any expensive objects. The father added, that they will probably be doing the same in the case they had a very normal and active child. The mother also explained that their child's behavior with strangers is very special, she is very friendly and asks them questions that they consider inappropriate, such as asking a total stranger - do you have pets in your house?, what kind of animals do you have? and similar questions. She is not a shy child, she is very friendly and also very polite. Sometimes she seems to understand when one talks to her, other times she does not understand, prompting more explanations. It is difficult to carry on a conversation with her because of her comprehension, and because she gets stuck in her idea and wants to continue with her own subject and nothing else.

The father believes the child has a very unique way of drawing, with unusual shapes, details and color. "Many of her drawings depict animals with clothes, and have a great deal of detail and are interesting and entertaining. We want to help our child to continue developing her drawing ability. In the long

term we would like our daughter to be as independent as she can be."

They seem to believe much of the desired goals in therapy depend on the stage or level of their child's condition. The occupational therapist communicates with them infrequently, but when she does, she briefly mentions what she is trying to accomplish, and she has suggested a few things to do at home. She has invited all of the parents to observe whenever they want.

About resources and family friends they related that, at the beginning they attended all of the monthly meetings with the parents of disabled children, but now the father attends less regularly because of his travel. The number of families that meets in that area is about 15 and they think that the meetings are important for exchanging ideas. The mother added "some of these families do not have much time to socialize and they enjoy activities that are planned exclusively for them and their children." The mother is actively involved and a leader of this group and she helps plan activities with the social worker and family resource center, to bring speakers to the group, and to give information to the families about related activities in the community. Most of the parents in that group do not speak English and they both provide support and encouragement for them to discuss their problems. However, they think there might be parents who hear about this meetings 2 or 3 years late because referral is not timely.

The mother confirmed that the therapy that their child receives correlates

with the activities at home because they are helping her gain skills to be more independent, "it is similar because they teach her how to do things such as sorting, matching, folding, carrying, etc., and some of the same skills are practiced at home when she does her homework, and when she helps around the house. There is nothing in therapy that interferes with practices or beliefs at home."

The therapist uses a lot of games and toys and when she has not explained what she is trying to do the parents assume that the therapist has a goal or purpose in mind. The therapy has not required any painful procedures but if it ever did, they would consult with the doctor, and would solicit a different opinion to find out if there is something else that can be done. If there was a painful treatment to be followed at home the parents stated they would follow it in a way that would produce the same results with the least amount of discomfort to their daughter. The mother affirmed "of course, we would follow it for our child's benefit."

They had a good impression of the first therapist they met, but then, they did not know the difference between an occupational therapist and a physical therapist. The occupational therapist only told them how often she was going to be seeing their daughter. They stated that, back then, they would have benefitted a lot having gotten from her, or any one in the medical field, written information on occupational therapy and what they were going to do, so they could distinguish

between the physical and the occupational therapy. The mother stated, "There is a great need for simple, written information that the parents can read at home in cases like this."

Their daughter does not make any comments about her therapy sessions. If they ever have a question for the therapist they would not hesitate to ask, and finally, they think that their ethnic background does not interfere with a relationship between the therapist and them.

Case Three

Life Style and Customs

Family Three consists of a 33 year old divorced mother, her teenage son and her 7 year old son who has severe mental delay and mild autism. Fourteen years ago she emigrated from urban Peru to the United States with her parents and first son. Later she married and had a second son. This marriage ended in divorce a few years later. The family members speak both English and Spanish at home. With her older son,this mother speaks more English than Spanish.

This mother considers herself fully employed, her major responsibility is to care for her disabled child for whom she receives a small pension from the state. She also provides care and supervision for her teenage son; and from time to time takes classes related to her child's development and behavior. She is very glad to care for her son, thus preventing him from being sent to a residential facility

where, she said, it would cost more money to the state. She considers her pension a minimum wage, "but being close to my little son is very important to me," she added.

The oldest son's responsibilities are helping around the house and occasionally watching his youngest brother when the mother needs to run errands. After her youngest son was born this mother went to work full time for a couple of years. She was employed in the research department of a local bank. She got divorced when the child with disability was one year old. It was very difficult for his father to accept his son's disability, because the child has many impediments. However, she added this was not the only cause of their divorce.

This family celebrates Christmas and Thanksgiving. She explained that her mother and father live in the next town, and that her mother works a lot and does not see them often. She also said, her mother does not understand much about her child's condition and that she does not rely on or ask her mother to help take care of her child. She does not have brothers or sisters and her 93 year old maternal grandmother lives with her parents.

The older son is 15 years old and goes to junior high school. The mother enforces curfew hours. During school days, and past 10 p.m., he is not permitted to stay outside the home, watch television, receive calls or use the telephone. She affirmed that until now he minds and respects her.

When anyone is sick, the family goes to the doctor or the hospital. They do not use any type of alternative medicine. When the mother was asked if she ever goes to curanderos or believes in other types of treatment, she laughed and answered, "No, no, I attended the University three years and I have continued to take self-interest classes. It is possible that people who live in remote areas and small villages where they do not have access to medical services, might still believe in different types of cures. But anyone who has lived in cities, especially the capital, and has a little more education does not seek alternative medicine."

A typical day for the mother starts at 7:00 a.m. She prepares breakfast and helps her son get ready, and then takes him to school. Upon returning home, she does the household chores especially jobs that generate noise, like the vacuum cleaner, the dishwasher, the washer and dryer, because noises frighten her disabled child. When he hears loud noises he screams, cries, and hides. In the morning she also prepares the evening meal because when he returns from school he requires constant supervision. On their way from school they sometimes stop at the park. At 6:00 p.m. she helps him bathe and in the evening they watch the Spanish TV channel. They both enjoy the soap operas.

This mother described how difficult it was for her the first few years. "I have lived some rough times the first few years," especially, she said, because she did not have help. The first couple of years after her son's birth she continued

working full time in a bank, and the child was cared for by a baby-sitter who did not know how to care for him. The baby-sitter told the mother that her son was very difficult and did not take much to eat. Apparently the baby-sitter chose not to "struggle" to feed him and the child slowly became malnourished and dehydrated and became very sick. When the mother took the child to the hospital they advised her not to continue with the same caretaker. She stated, that at that time, she had to make a decision that changed her life forever.

> I had to decide if to continue working and have my son sent to a state institution permanently, or to resign to my job. I chose to take care of my child full time forever. For a couple of years I had to be on welfare, I did not have any other choice, it was more important to see my son in good health than have the independence to work outside of the home, and I dedicated all my time to take care of my sons.

She explained that, slowly she started to become acquainted with the state programs. The hospital gave her very little information about where she could get help. When the child was pre-school age, the hospital referred her to a school for children with disabilities; and through other parents she discovered how to receive monthly income from the state, which she calls "my salary." The ex-husband pays child support for his son, but for the oldest child who is her son

only, he pays medical insurance. The family lives in a modest rented house. The mother described her economic situation is OK.

Occupational Therapy for her Son

The child is 7 and 1/2 years old. He was diagnosed as severely mentally delayed and a couple of years later "with autistic characteristics" was added to the original diagnosis. The mother stated that mentally her son is at the one or two-year old level in some things, and at a three-year old level in some others. His coordination is very poor and he does not speak.

Since the child was 6 months old he received occupational therapy through the program, Assistance to Individuals with Disabilities (AID) until he was 3 years old. From 3 to 5 years of age, the child did not have therapy because the school district did not consider it necessary, and the mother added that, she was starting to find out about other resources. So when her child turned 5 years old she requested occupational therapy through the IEP (individual education plan). At this age, her son was very resistant to try to learn activities appropriate for his age level, his coordination was very poor and when he was screened he qualified for therapy. He also had behavioral problems related to his mental delay; when he wanted something and because he cannot speak, the child would approach his mother and slap her face. The mother said that this was the behavior that presented the most challenge to endure and to change.

> Little by little, I taught him to approach me and kiss my cheek when he wanted anything. It was a very difficult thing to teach him and his first reaction was to throw himself on the floor and to scream and kick. It was difficult because I had the temptation to give him what he wanted and have him quiet down quickly, but I thought if my child was to learn to ask me in an appropriate way, I had to be firm and persistent.

On three occasions during the interview he approached his mother to ask for juice, cookies and a toy that were out of his reach, and every occasion he kissed his mother's cheek, then held his mother's hand and pointed in the right direction to get what he desired. The mother, herself, was surprised and proud that she was able to overcome and reform that specific behavior.

The mother believes that her son needs ongoing occupational therapy to improve his mental and physical condition. She stated that even though he is profoundly delayed in his development, she has hope that his mental capacity will allow him to learn some living skills, such as to go to the bathroom with minimal assistance. This will enable him to stop using diapers. Also, she thinks that eventually he might be able to learn to eat without assistance or with minimum assistance. The child can now wash his hands with assistance. He does not like to brush his teeth because he has an aversion to having his mouth, face and head

touched, especially, and generally has an aversion to anything that goes into his mouth. He does not like stuffed toys. The mother also admits that she has some tactile defensiveness as well. She knows that there are certain things that can not be expected of him, because, she says, there are some things he can not physically tolerate. His health is much better now but the first few years of his life he was often sick with colds, bronchitis, ear infections, had his tonsils removed, and had eye surgery. "The situation has been ugly, I have had some difficult times," she exclaimed. If his health gets better she said, she would like to continue going to school to learn more about developmental disabilities and become a case manager.

In reference to how other members of her family feel, she said that they express a lot of compassion for her son. "Sometimes it is a bit too much. My parents and grandmother tell the boy 'poor child, poor child,' and I feel somewhat uncomfortable, because in reality, he is not so helpless, he has a very, very happy life. He is happy, he lives in another world, and he doesn't lack anything, but I do not let do every thing he wants either, and I have learned many useful behavioral techniques appropriate to his condition." She continued, "disabled and all, these children are very smart when it comes to knowing how to get an adult's attention. He is very aware of everything I do, and knows some of my family members' peculiarities. He observes me all the time, knows me very

well and I know him very well, too."

The mother also stated that she is hoping that his IEP will include some vocational skills. She is hopeful that someday he might be able to work in a sheltered place. She thinks she has a lot of control in therapy goals through the IEP as well as at home.

The mother's major resource for moral support is her small family; with some hesitation she added that she knew they were there to help her if she needed them. She has one close friend who lives nearby. She also relies on her older son. He is very kind with his brother and takes care of him when the mother needs to go out.

The occupational therapy correlates with everything he does at home, she concluded. On one occasion during an occupational therapy evaluation the child refused to cooperate, and the therapist could not evaluate the child. The mother thought that the therapist gave up too soon and seemed afraid to approach and help him to understand that she wanted him to sit at the table. The therapist concluded that nothing could be done with the child because he was too profoundly delayed, to which the mother responded that she was too afraid of him. Based on that experience, the mother asks any new therapist if they have experience with children who have behavioral problems. She continued, "It is different to teach a child with Down's Syndrome, with C.P. or autism, than it is to

teach a child who has this type of reaction to new situations, reaction that is called behavioral problem. They cause a lot of turmoil, but we can not consider them hopeless, or formulate an opinion based on one visit."

The occupational therapist now engages her son with small crackers. The mother related, he would almost always battle and refuse to go to therapy for the first 5 or 10 minutes. He threw himself on the floor and refused to go with the therapist. The therapist continued the therapy session, and totally ignored his unruly behavior. The mother stated, that this was one of the things she really liked about this therapist, that she did not let his behavior intimidate her. "My son had behavioral problems that made anyone nervous. He did a lot of testing, but he has come a long way, and now he cooperates with the present therapist and allows the therapist to move him through the exercises."

She thinks that games and toys are the most natural ways to gain children's attention and they are very appropriate to use in therapy. She knows that the therapist has certain goals in mind when she is playing with him. When the therapist tried to teach her child to ride a tricycle, the therapist said the child was not ready to learn yet. The mother requested that all three wheels touch the ground, and the child was able to keep himself on the tricycle. "I like occupational therapy; it is very useful," she stated. If there is a painful procedure to be followed at home she would comply as long as she knew the reasons.

When she met the first occupational therapist, she said, she remembers worrying about the negative opinion the therapist was going to get, because her child's behavior deteriorated instantly and drastically. She added, it is very difficult for everyone, but warns therapists from forming a false and negative opinion about a child's case, in similar situations.

Even though the child can not express his opinion about occupational therapy, the mother said, she knows that he is used to it now because he rarely protests about going. When he does not like something he has two reactions, one is to squirm when they direct him, the other is to keep still and not respond; if he is forced, he still throws himself on the floor and kicks. He has come a long way, the mother reiterated. He recognizes the places they frequent: his neighborhood, the park, and his grandmother's apartment complex, but he does not recognize dangerous situations. He likes television, and he has his own TV set. He has two videotapes that he views repeatedly. His mother said, "he has adapted to his world."

The mother feels comfortable asking any questions of the therapist and believes her ethnic background does not interfere with her relating to the therapist or vice versa. She is Catholic but attends church infrequently and informally. She does not feel that she must go to mass, but rather, she stops and goes inside the church whenever she feels like doing so.

Case Four

Life Style and Customs

This family is composed of the 33 year old father who is from rural Mexico, the 40 year old mother who has lived in both rural and urban Chile and their two year old son who was born in the U.S. The mother has lived in this country 14 years, and was previously married for 3 and a half years. She is now divorced and did not have children in the marriage. She now lives with a man who is the father of her only child. He is from rural Mexico. They have been together for the past 4 years. They both work full time, both take care of their son and speak Spanish at home. When anyone is sick they go to doctor, and the local hospital, or clinic.

The father watches the child during the day while the mother works and the mother cares for the child in the afternoon. The mother works at a busy retail store as a sales, stock and cashier clerk from 6 a.m. until 2:30 p.m. The father works at a hotel as a bellman from 3:00 in the afternoon until midnight. The child goes to child care about twice a week to allow for schedule changes in both of their jobs. When the father is absent, usually on a trip to Mexico, the child is in child care full time.

At home the father helps with all the housework activities and does most of the cooking. They both pay certain bills, but she pays for most of the expenses

because she makes more money. Also he uses most of his money in the construction of a home in Mexico. She assumes this construction will take 4 or 5 more years and he wants her to come to live in Mexico with him when he finishes building the house. However, she wants to buy her own home here and is indecisive about going to live permanently in Mexico.

A typical day for the mother starts at 4:00 a.m. "I allow for 20 minutes extra time to warm up my old car, eat breakfast and prepare my food to take and save money." She starts work at 6:00 a.m. and has a half hour for lunch with one break of 10 minutes length. Her job demands standing and walking all of the time and it involves a lot of interaction with customers, which she likes. Most afternoons she stays home with her son. On occasions she runs errands or complies with appointments.

She said that most decisions are made by mutual agreement, but because she has lived in the apartment longer than her companion, and all possessions and debts are in her name she stated she feels independent and in control. She considers her economic situation low and her salary very meager. "Muy baja (very low), I only make $5.00 per hour, and this is very little because sometimes I have to pay half of this in child care." She is planning to return to school and has applied for financial aid which has been approved. She needs to make her final commitment stating the starting and ending dates of her intended schooling. She

finds this difficult because her partner, the father of her child, goes back to Mexico to continue building his home and will continue to go for one or two months at a time every year. She does not receive encouragement or support from him to continue her education. She stated, "That is the way he is, he does not think going to school is going to change things for me, and urges me to continue working." He has young relatives whom he could ask to help them with the care of their child, but he is concerned with other problems that this might bring, for instance, the problems of having a teenager, partying, or having to deal with an unwanted pregnancy. Her mother and sisters all live in Chile and her sisters are all married. Her mother does not wish to move to the U.S. even though she was able to get a resident visa for her.

Occupational Therapy for her Son

The mother related that her pregnancy developed without any complications. However, she had a difficult labor and prolonged birth, at which time, the mother is almost certain that her child suffered brain damage. The baby was forced out with great effort and with the use of forceps. The baby's head and face were injured and bruised, the baby had to be fed with a gastrointestinal tube for two weeks and remained in the hospital for a month after the birth. She visited the baby in the hospital every day.

The child is 2 years old now and presents with difficulty focusing his eyes

and paralysis of his left hand. He did not crawl, but a few days after his second birthday started to walk, and has a vocabulary of about 10 words. His right hand is very strong and he uses it continuously. During the interview, he wanted to participate and constantly made sounds to attract attention. When the talk was about his right arm, he started stroking the researcher's arm gently. He seemed to understand most things that were being said, and the mother stated, that he understands a lot, and is a very affectionate and happy child. The mother affirmed that most of her child's delays are physical and she believes that he learns most things appropriately for his age. When she talks about her son this mother displays a great deal of love and shows him a lot of affection. She stated, "He is very smart."

She confided that the father does not think their son needs therapy, and that he tells her that she is wasting a lot of time taking him to therapy sessions. He believes his son is strong and is doing so well that everything is going to be all right, and that their boy is going to get well. Nonetheless, the mother is requiring of the father to take their child to therapy every other time and it is a requirement that if he does not comply with, will cause their separation.

During the first 6 to 8 months the child received physical therapy. He did not move on his own. The child started receiving occupational therapy at about one year of age, the mother added, "too late, I think he should have been getting

occupational therapy much earlier." The occupational therapy takes place in conjunction with physical therapy, and instead of getting one half hour of each, both therapists work together for one hour.

She affirmed not having any hesitancy when she has questions for the therapist. The therapist recommends certain activities and exercises to be carried out at home, and she tries to be involved in all plans and decisions that are made. The treatment practices and goals correlate with the activities at home. Almost always the recommendations are appropriate and she continued, "I like very much all the things the therapist does during therapy. I should do the same things at home more often; he likes to play with all kinds of things and I like play therapy." If the doctor or therapist recommended a certain procedure that is not too painful she said that she would follow it, if it is for her son's benefit. She does not believe her ethnicity influences in any way the relationship with the therapist.

In reference to her sources of moral support she said she communicates with her mother and sisters in Chile. She also related that a few years ago a Brazilian-Peruvian couple founded a Baptist church in her area. The first meetings took place in her apartment, which then was in the basement of the building. Now she occupies a small apartment on the third floor of a 4 building complex. She frequents this church about once a month and considers the pastor and his wife one of her sources of moral support. "They are my friends, I call them when

I need them and they come. They are almost more supportive than my partner." Her other two sources are her partner and her son. She believes her son inspires and moves her to struggle in life and to provide for him and for her. She keeps in touch with an old friend from Chile, but talks to her infrequently. She does not have the close friendships that she kept before her marriage. She stated, "My partner does not have any close friends. He is very close to his big family, who lives in town. He does not like for me to have any friends. I am busy with my work and my son, I do not have much time nowadays, and my work provides me with a lot of human contact, maybe that is why I do not need to spend much time now with other people."

There is a lawsuit pending regarding her case because when she was interviewed for financial aid she stated that she believes her labor and delivery were not handled appropriately at the hospital and that the doctor who delivered her baby came in and intervened too late, and that such delay as well as all the physical trauma to her infant's head and face inflicted with the forceps, are the direct cause of her son's brain damage. She also conveyed that the hospital tried to intimidate her after the lawsuit was initiated, by sending someone from the child abuse agency to inquire about child abuse. But she stated that the baby was kept in the hospital for one month following his birth, and that her son had his disabilities from birth on.

Case Five

Life Style and Customs

This family is from urban Peru and is composed of a father who is completing his last couple of years in the Peruvian Navy and still lives in South America, the mother who is 42 years old, a daughter 22 years of age who is living in Peru and going to the University, a daughter 17 years old and a son 15. The mother and the two younger children immigrated to the United States several months ago. They are living with relatives that immigrated many years ago.

The mother and her two teenagers live in a large home shared by a total of 10 people: four adult sisters, one adult male, three teenagers, and two young children. One of the sisters is married and the husband lives in this house, one sister is separated, one sister is single, and the interviewee is married.

They all contribute toward paying the expenses and take part in all of the home responsibilities as well as in the care and supervision of the children. The teenagers and young children are taught to pick up after themselves. They speak Spanish at home.

This family generously celebrates birthdays with typical Peruvian dishes, music dance and lively talk. They also celebrate the new year in a similar manner as well as other happy family events and dates such as completion of school, attainment of scholarships, farewells, arrivals, baptisms, etc. When someone in this

family is sick they receive traditional medical care and do not seek any other type of care.

The mother who provided the information for this case study has a 15 year old son who was born in Peru and has Down's Syndrome. A typical day for her starts about 7:00 a.m. The first duty that she performs in the morning is to prepare breakfast for her son and make sure that he is ready and waiting for the school bus before she leaves for work. She leaves for work with two of her sisters before the school bus arrives. They clean apartments until 1:00 p.m., at which time they return home to prepare the mid-day meal. She then rests, spends time with her son when he returns from school, and at 4:00 p.m. leaves to go to work again as a janitress until midnight.

She stated that the economic situation is stable, and she does not worry if any one in her family loses his or her job because they are always there to help each other until they get a job again. "We are all concerned about each other's well being, and we make decisions democratically. We give, we borrow from, and lend to each other without even having to ask for it, that is the way we are." The sister who has lived in the U.S. longest is the one that owns the house and contributes with more income; she occupies two rooms and is consulted when major decisions are made because she is more experienced and is the one who is most helpful to everyone. The mother explained, "even if we go on living in

separate homes, we still will continue to help one another, and continue to be close."

Occupational Therapy for her Son

The mother believes her 15 year old son to be more advanced socially than other children of his age and with his condition. Academically he is at a 7 or 8 year-old level. He is very friendly, loves to be around people, especially his 15 year old cousin, whom he tries to imitate constantly in all things. He is very polite, likes parties, loves to dance and dances very well. He can write phrases, add and subtract 2 columns, and likes to draw. As an infant in Peru he had some therapy; this type of therapy was mainly socialization, music, dance, exercise, and at the same time the mother attended classes for the parents in the same school her son attended. At seven years of age the child went to a school for children with disabilities partially paid by the Peruvian Navy. This was a private school where he was taught basic school subjects, reading, writing, arithmetic, and science. There he was expected to do homework, pass his grades and wear a uniform.

She related that her family is used to her son's disability, and feel very comfortable around him. "I have to remind the teenagers and the children, especially my daughter, that he is a child with delays in his development, because they all treat him as if he was a normal child, and sometimes they demand certain

behavior he is not able to perform. Even myself, he is so independent now, that sometimes I think he is not delayed. He does everything independently; however I and my daughter need to check that he does things right."

The mother explained that the demands of his school or therapy are none. "He is a very easy child. He carries his own keys and has been doing so for a few years now. When he returns home from school there is almost always someone at home, in Peru or here. Now he is learning English. He is learning it fairly fast because we lived in England two years when he was 8 months old until he was 2 and a half years old."

He is also learning some auto mechanics, and how to run a small business, besides the basic school subjects. The mother expresses a great deal of appreciation for all that her son is being taught, and for having an IEP contract, which she believes is good anywhere in United States schools. She is happy to know that anywhere she moves, her son can have the same kind of education.

The mother is very amused and in awe of the school's approach to teaching these children vocational skills that prepare them to be useful, working members when they become adults. At school, she related, in the class "How to Run a Small Business":

> The teacher and children have developed a routine where they bake cookies and sell them on the school grounds. Each student in his

class has different jobs: some buy what they need, some bake, some sell, some keep track of the expenses and earnings, and each one has a small bank account where they learn to keep a savings and a checking account. They also recycle aluminum cans, sell them and accrue profit, and they still make time to take the children on outings to visit different places almost every day of the week!

She thinks she does not have control of the direction that his therapy takes but she said, that the goals in the IEP are what she wanted for her child anyway. One of the reasons she decided to immigrate it was to give her child the opportunity to learn skills to enable him to have a job. She continued: "In Peru there are no jobs for young men who are able, much less for young men who are disabled. Here there exists the hope that my son can have a job in the future, and will not a big burden to anyone."

The occupational therapist had never required her to perform any painful procedures but she says that if it was for his benefit she would comply with it. Her first contact with an occupational therapist occurred in London and she gained a very good impression of them. She related that there, she learned that therapy was not going to return her child to normalcy, but that he was going to learn many skills. Before then, she was not sure what to expect and kept hoping that therapy was going to reverse his condition. She said the therapy in Peru was

more geared to the mother's psychological well being and dealt more with how she reacted to the news that she had had a child with Down's Syndrome. She then started to confide and reveal the despair, anguish, hopelessness and rejection she felt after her son was born, and described the following: "How was it like to know that my child was born with Down's Syndrome? "It was incredible, it was devastating! I rejected my little son..."

Taking a deep breath and after a long pause, she continued,

> I rejected him after he was born and for several months after. During the pregnancy, I suspected there was something wrong because the baby did not move or kick, as my other babies had done. During the third month of pregnancy I was seen by an endocrinologist who prescribed medicine for the thyroid. I believe this is what caused my son's disabilities. When he was born he did not cry, he made gurgling sounds instead, and could not breathe normally. About five hours after the birth the pediatrician informed me that the baby had several Down's Syndrome traits, to which I reacted with desperation, rage and I lost my mind. I told the hospital staff I did not want him, I wanted them to kill him. I lost my sanity temporarily. I kept thinking of my mother-in-law, you see, she is from the country side. I have also heard that sometimes,

children who are born with disabilities out there, are hidden and raised in secrecy and without seeing outsiders, as if this was a bad thing. I went into shock, I could not think straight and I could not help it.

She continued,

My husband was my salvation, he rescued me from all that pain and sorrow. Slowly, he made me see why we were not going to get rid of our child. He talked to his mother and explained to her, and made her understand. My mother-in-law thought, that maybe, the baby was born with oriental facial features because my husband and I used to go to see Kung Fu movies, those movies were popular then. His family and my family accepted my child from the beginning. But I was so terribly depressed that I kept rejecting my child. I am so sorry, I withheld love and affection from him. I recognize it now, and I force myself to talk about it because it makes me understand more what I was going through. The only thing I did those first months was to take him to the doctor because he was continuously very sick with different ailments, and to take him to therapy from the age of two months old. My sister, who was a teenager then, gave him a lot of love and affection, and so did

everyone else in the family.

About six months after the baby was born, my husband was awarded a scholarship to study for two years in England. I stayed in Peru with my children and my mother. Soon after, my husband asked me to go to England to join him. He arranged for his mother to take care of our two daughters and for my mother to take care of our son, in Peru, and he had me travel to England. Before I left for England, my son got gravely ill and I spent all my money on doctor's bills and medicine. I kept taking him to doctors and specialists and stayed up many nights watching that his fever did not go up dangerously high. But I still would say that I did not love my child. My mother would answer, "If you do not love your child, why are you so persistent in saving his life?" When my child got well, 8 months old by then, I traveled alone to England to join my husband.

About two months after she arrived in England, she started to miss her son very much, and asked her husband to send for the baby.

I could hardly wait to have him with me. We sent for our son and I was very happy after my son arrived. Soon after, he started getting occupational therapy. In England, I had the opportunity to see other children who had more severe disabilities, and I started to

consider my child's case mild compared to other cases. In addition, my child was developing rapidly and showing good learning capability. He was very affectionate, cute and happy, crawling everywhere and I couldn't help it, but to love my child as I never had. After the two years stay in England we returned to live in Peru until recently when I and my two younger children immigrated to the United States.

Responses Addressing Old Beliefs

In response to the questions that were asked regarding the traditional cultural beliefs of Hispanic families, all five of these families answered "yes" to the questions regarding the grandmother matriarch and many female relatives become involved in the care of the children and Hispanic women believe that a pregnant woman can cause permanent damage to her fetus by experiencing a strong emotion. Four of the five families answered "yes" to the question about the Hispanic mother dressing her child until 5 or 6 years of age.

They all answered "no" to the question regarding divine punishment causing physical or mental disability. Four of the families answered "no" to the questions regarding Hispanic parents caring for their children, then children caring for their aging parents; Hispanic children being spoon-fed and given sugared beverages at bedtime until they are 3 to 4 years of age; Hispanic women believing

that a pregnant woman can cause permanent damage to her fetus by making fun of someone with physical defect; and the evil intentions of others, and acts of nature, for example, lunar eclipse, can cause physical or mental disability. (See Table 1)

Research Questions and Answers

1. What do Central and South American Hispanic parents value in relation to occupational function?

Reading each case study, one can get a detailed description of the different skills these parents from Central and South America desire and strive to teach their children. The case studies show that the children have had different physical disabilities or challenges since birth and what is expected in each individual case varies in accordance to the child's disability. Values and skills mentioned by their parents can be summarized as follows.

All of the parents in these five case studies expressed a desire to make their children as strong and independent as possible. All of the parents spoke about the importance of developing skills to promote independence in the execution of activities of daily living such as feeding, bathing, dressing and picking up after themselves. A second but equally important goal of the parents was to teach their children to control their behavior. There was no mention of strict rules imposed on their conduct, but it was expected of the children to comply in a

Table 1

Old Beliefs and Values

	YES	*NO*	*SOMETIMES*
The family is the most important source of moral support one can have in The United States	3	2	0
The family is the most important source of economic support one can have in Central and South America	2	3	0
Hispanic adults take care of their children, and when the time comes, the children will take care of their aging parents	1	4	0
The Hispanic mother often assumes the role of "doer" for her children	3	2	0
The grandmother matriarch and many female relatives become involved in the care of the children	5	0	0
Hispanic children are often spoon-fed and given bottles of sugared beverages at bedtime until they are 3 to 4 years old	1	4	0
The Hispanic mother continues to dress the child until he or she is 5 or 6 years of age	4	1	0
The woman in the Hispanic family is the person responsible for communicating and establishing the family's social relationships	1	3	1
Hispanic women believe that a pregnant woman can cause permanent damage to her fetus by making fun of someone with physical defect	0	4	1
Hispanic women believe that a pregnant woman can cause permanent damage to her fetus by experiencing a strong emotion.	5	0	0
Divine punishment can cause physical or mental disability	0	5	0
The evil intentions of others, and acts of nature, for example, lunar eclipse, can cause physical or mental disability	1	4	0
Hispanic mothers of children with physical or mental disabilities feel very guilty	2	2	1
Hispanic mothers of children with physical or mental disabilities overprotect and limit the child's development because of their guilt	2	1	2

subdued manner and exhibit a polite approach toward parents and adults. Also, safety was raised by most of the parents as a goal and as a means to obtain other functional skills. For their future adult life the parents expressed a desire for their children to learn vocational skills that will enable them to participate in some type of employment and have some means to be somewhat economically independent. This value was stated even by the parent whose child had the most disabling disability. This expectation does not seem unrealistic because the parent explained that even doing a simple sorting task would be a challenging job.

2. What impressions and opinions do Hispanic parents and children express about referral, assessment, and practice of services?

A synthesis of the impressions expressed by this small group of Hispanic parents about referral, assessment, and practice of service, was mostly favorable. They all reported having a good impression after meeting the therapists. In two of the cases, however, referral presented a problem for the parents. It appears that referral to the appropriate agency was not made and the parents believed they received help but that it was not early enough, and not nearly as much as they believed their case required. Also uncertainty as to the jurisdiction and role of some agencies was also expressed.

Assessment was a concern in two of the cases because their child's behavior deteriorated around strangers and when confronted with non-routine

events. In general, parents expressed satisfaction with the assessment procedures and allotment of time to evaluate the children's condition.

Ethnicity appears to be a factor of no concern when initiating and continuing interaction. Only in one case was there dissatisfaction with the treatment received at a medical facility, but this occurrence did not involve therapists.

Criticism was more related to the lack of information and clarification once a diagnosis had been given, rather than to the therapists' approach or delivery of service. A recurrent comment during these interviews was that there was no explanation given when a diagnosis had been formulated. The diagnoses in these cases caused anxiety and distress up to several months in some cases. These occurrences prompted the following questions: Are the therapists too careful, and do they avoid making any attempt to explain what could be occurring? Do they avoid discussing the diagnosis? Is there a need for simple physiological explanations when parents are given a diagnosis that is not common?

Another factor related to practice was the parents' inability to tell the difference between physical and occupational therapy and the constricted view of the therapist's role which was implied in two of the cases where the therapist was only seen as helping the child improve muscle function and nothing else.

3. What are some of the cultural norms and customs that compliment or

interfere with occupational therapy goals?

Questions that addressed norms and customs generated the following findings. None of the customs described in these cases seemed to interfere with treatment itself. In one of the cases the father believed that his child was going to get well and that he does not need therapy; this belief might interfere with treatment but this interference would not be due to cultural belief but rather to lack of knowledge of his child's condition.

In reference to impressions expressed by parents, the following comments might be related to cultural differences as well as to individual differences. It is well known that most Hispanics display among themselves friendly gestures and warm-hearted greetings and it was of interest to find that a Hispanic father felt differently when he received this type of treatment from a Non-Hispanic American therapist. The therapist was warm and friendly rather than businesslike. The father was very puzzled by her behavior. It is known that most Americans do not greet or behave in such a manner, and this behavior is not expected from them by Hispanics. Among Hispanics this behavior is usually reserved for long time acquaintances, friends and relatives, but not for someone recently met. It is also reserved for social and casual occasions and in general is not displayed in business or clinical environments.

While friendship is highly valued and cultivated in Central and South

America, only the Case Five family reported having several friends and actively associating and including them in their life and celebrations. Friendship did not appear to be a strong support system for these families. Even though their moral support came mainly from their family whether large or small, only one of these five families relied heavily on their relatives to help them with their children, and to alleviate their economic and social needs. Neither were Godparents mentioned as a source of moral support; and only one parent whose support system appeared devoid of friends and nearby relatives mentioned church as a source of moral support. This finding raised the questions: Do the responsibilities of having a disabled child restrict the parents' time and impede the cultivation of friendships as they would like? Do they feel as a group less connected? Or do they simply perceive others in society as lacking personal interest and displaying coolness and extreme privacy?

Hispanics in Central and South America have many friends and friendships that serve to assist in getting a job, securing admission to certain schools or in obtaining other social services. These friendships may be viewed as utilitarian relationships but this is a cultural phenomenon that is occasioned by economic circumstances. From the Hispanic perspective, friendship is that and more. Friendship is a sincere concern for each others' well being and socioeconomic success, and it is more than a mere opportunity to spend happy times and enjoy

mutual interests. That it is why sharing information and exchanging services is common.

There was a consensus on the holidays celebrated, Christmas, New Year's day, and in most cases, these holidays are celebrated similarly as the rest of the society. Children's birthdays are celebrated with family, friends and neighbors.

There was also consensus on medical care practices; none of these families sought non-conventional or non-orthodox treatment. Six of the seven parents have spent most of their lives in urban areas and all seek modern medical treatment here and in their country of origin. This finding correlates with what Miller et al. (1979) affirmed about medical treatment preferences by people with some education living in urban areas. Regarding education, of the seven parents interviewed, most reported having finished high school, one has a professional degree, and four have some college education.

When describing characteristics of the Hispanic culture, it was commonplace to find that machismo is a favorite topic of most writers. A definition of machismo comprises the concepts of male dominance, virility and outlandish self-confidence. In one of these five case studies, it appeared that the relationship between husband and wife presented a subordinate role for the wife and it was evident that the way they related to one another was characterized by their age difference of 12 years. It could also be attributed to the inexperience

and passivity of the younger wife and not to a male-dominant attitude of the husband. In two of the cases the women expressed being equal partners; and in the other two cases the women expressed feeling independent and running their lives as they please.

Of the five women interviewed for this research, two did not work outside the home, one had a part-time job, one had a full time job and one held two jobs. Two of these two women made more money than their partners. And all of the partners had full time jobs.

Summary of the Responses Addressing Old Beliefs

The answers to the questions regarding the traditional old beliefs and values seemed to also confirm the statements of Miller et al. (1979) about popular beliefs and folk medicine. North Americans pride themselves on their rational thinking, scientific viewpoint, and lack of superstition, though this is a fairly recent development. It is a characteristic of Western culture that rational and logical thinking replaces older belief systems, including superstitions. One major factor of this process is education, and among the educated in South America, (and Central America), superstition holds no more power than it does in the U.S.

CHAPTER 5

PROFESSIONAL IMPLICATIONS AND SUMMARY

Implications for the Practice of Occupational Therapy

The Occupational Performance Frame of Reference lists the areas of expertise of the occupational therapist and the areas of concern within the profession, as shown in Figure 1. These concerns are divided in two major areas. The occupational performance skills, which are: self-care, work, and leisure/education activities, and the occupational performance components which are: motor, sensory/integrative, cognitive, psychological and social functioning.

Using this generic frame of reference to discuss these five case studies of Hispanic families in the self-care and work activities areas there seems to be little need for intervention; however, there does seem to be a need to integrate play/leisure activities for these families. Under the performance components or second level of the occupational performance frame of reference, three of the five areas of therapy need to be integrated when working with the Hispanic parent of disabled children. These three areas are the cognitive, the psychological and the social functioning of these families.

The two areas that are at present being utilized in therapy are the motor

functioning and sensory integrative functioning while providing therapy for the disabled children. Therapists' proficiency in these areas is such that it gives the parents the idea that this defines the occupational therapists' expertise; however, these two areas are not the only two areas of their practice.

After reading the cases it is evident that the cognitive functioning area needs to be integrated from the beginning of occupational therapy. All of the Hispanic families, in one form or other, related how comprehensive, written and verbal communication, problem solving, time management, conceptualization, and integration of learning was essential in their case. These families all wanted to know more about their child's diagnosis, what to expect and how to proceed. Diagnosis seemed to be a key point to their understanding of what was to follow, either with safety, behavior, or vocational training.

The fourth performance component that needs to be implemented is the psychological functioning; and the fifth is their social functioning. Besides the disability of their children, an important factor that interferes in the normal development of these areas is their state of being immigrants. Immigration is a very unsettling state of being, ranging from cultural shock to cultural bliss. Whether there is a short or long adjustment period after immigration, there still remains the child's disability with which to cope.

Because these families are recent immigrants, an important source of social

contact is the therapist, and when the therapist does not make him or herself accessible, there is a lost opportunity to help these families integrate into the new environment, and to deal with the medical and educational systems more effectively. Language in most cases did not appear to be an obstacle. In these five cases, there was at least one member of the family who spoke English, and almost always there seemed to be people available and willing to translate in a case where a translator is needed. This seemed to be an underutilized technique which otherwise could bring invaluable benefits.

In corroboration with Anderson's and Hinojosa's case studies (1984), Pratt (1989), as well as Moersch (1989), these five case studies of Hispanic families exemplified these authors' ideas and claims, that families that have more interaction with the therapists were most satisfied with therapy and seemed to have been able to bring change in their lives more smoothly, confirming that the therapist's partnership with Hispanic parents is sometimes, indeed, more significant that the time spent with their children.

It is still commonplace for Central and South Americans, who are almost never alone, to get to know their neighbors and rarely adhere to what some Hispanics perceive in the U.S. as extreme privacy. Hall (1959) related how North Americans living in Latin America complained that "they felt left out of things." This implies that a person's interpretations of a new place and new people may be

influenced by being in the newcomer role in the new country, city, or neighborhood, regardless of ethnicity.

In reference to their psychological functioning, the multitude of feelings that parents of disabled children experience were expressed by these Hispanic families. This prompts the need to encourage parents to broaden and strengthen their moral support system, as well as to support one another. The support system should be considered seriously in immigrant families who left their family abroad, and because raising a disabled child seems to be, in certain cases, a limiting factor in developing friendships as well as limiting social contact and recreation outside the home. Furthermore, occupational therapists working with Hispanic families should be familiar with other agencies that specifically help Hispanics integrate, educate and function in their new society.

Social functioning, dyadic interaction (two person), and group interaction, should be initiated, encouraged, promoted and facilitated with immigrant parents of disabled children of the same and of different ethnic groups. In the Hispanic culture, in particular, women like to be invited to join a small group where there is at least another woman of the same cultural background, and where informal conversation can take place. Social functions that are scheduled with a flexible starting time of about two hours works best for most of the families who have children with disabilities. For example a gathering or an outing with a flexible

time between noon and 5 o'clock fits well with most families.

This will honor the Hispanic preference for polychronic time which Hall (1983) mentioned in The Dance of Life. To Hall's explanations about monochronic and polychronic time is important to add that the new immigrant may run his private social affairs following a polychronic time; however, when Hispanics immigrate to the U.S. they may or may not know Hall's definitions of time, but they know, that this society runs on a tight schedule, because this characteristic of the American culture is a universal bit of information known by most; nonetheless most recent immigrants prefer scheduling most of their activities with greater flexibility that this society demands.

Implications for Further Research

Many topics can be explored regarding the Hispanics of Central and South America. Information which can contribute to a better understanding of this ethnic group is needed. There are times when one ethnic group or another is targeted for political and social reform, but it is a professional responsibility to study the problems that confront the various populations to which services are provided.

A replication of this study with additional families using the same instrument, A-WCQ, would serve to expand the findings of this study. To this inquiry, it would be of interest to address socio-economic class and beliefs related

to this difference.

Another study would inquire of therapists who provide services to Hispanics about cultural and medically related topics of concern that they encounter in practice. Other research could study particular areas of dysfunction in the Hispanic adult population.

Summary

This study involved interviews with five families from Central and South America who are raising a son or daughter in the U.S. with mental and/or physical disabilities. The number of participants were: one married couple from Guatemala, one married couple from Costa Rica, one divorced woman from Peru, one married woman from Peru, and one divorced woman from Chile. Four of children were born in the U.S.; one was born in Peru.

The main focus of this research was to get to know the Hispanic parents of children with disabilities, to inquire about their value system and old beliefs, to listen to their stories about their everyday lives, their feelings toward their disabled child, and their coping mechanisms. Secondly, the researcher sought to find out what these parents thought about occupational therapy, occupational therapists, and the medical and social system in which their children were receiving treatment. As advanced by Llorens (1984), and personal communication in 1994, identifying exterior environmental factors related to sociocultural adaptation gives

a more complete picture of the family, bridging some of the gap between what is written and what is known and experienced. This is even more valid when the statements have been expressed by members of the ethnic group being studied to another member or members belonging to the same ethnic group.

In relation to occupational function, all of the parents valued teaching independence, behavior control, safety and vocational skills to their children. Their impressions and opinions about occupational therapy and therapists were predominantly favorable. Referral to the appropriate agency and jurisdiction of the agencies were concerns expressed in some of the cases. Time and expertise were classified as being sufficient and thorough but there was a concern because the process was not preceded or followed with information about diagnosis or prognosis, nor was there certainty explaining the occupational therapist's role and expertise.

There were no norms or customs mentioned that interfered with occupational therapy goals. There was a consensus of the holidays celebrated and on medical care practices. Most participants reported having some college education and all of them came from urban areas. Most women worked and all of their partners had full time jobs.

Even though it is difficult to capture the richness of any culture and the many facets of any ethnic group from separate case studies, the usefulness of

studying these Hispanic families lies in the fact that the knowledge brought forth either confirms or refutes on a small scale, statements found in the literature. Initial review of the general literature presented some old values and beliefs, supposedly, held by Hispanics. Similarly review of occupational therapy literature yielded some old beliefs and values as well as one recent case study of a young Hispanic woman, where pertinent cultural values were also discussed. In these five case studies, some of the old values and beliefs found in the general literature and in occupational therapy literature were questioned to affirm a current day account of those values and beliefs as viewed by these five families. Of the fourteen beliefs and values queried, eight received consensus or near consensus.

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APPENDIX A

INTERVIEW QUESTIONNAIRE

ARCILA-WILKINS CULTURAL QUESTIONNAIRE (A-WCQ)

Culture

I am going to ask you some questions about every day life style and customs that you and your family follow.

- For how long have you resided in the US.?
- What language do you speak at home?
- Tell me how many people live in your home, and their relation to you? Can you describe your living situation?
- Can you describe the responsibilities that are carried on at home and by whom?

  What responsibilities and chores are assigned to your child or children?
- What holidays and important dates do you celebrate? Can you describe how you celebrate your favorite holiday?
- What norms or rules do you follow at home with your child or children? Can you describe how are they implemented?
- When you or anyone in your family get sick who do you consult for medical advise and treatment?
- Can you describe for me a typical week day, or, if I was following you, what would I see You doing throughout the day?

- Who takes most decisions at home and what kind?
- Who contributes with more income?
- How stable do you think your economic situation is now?

Occupational Therapy

- How capable is your child in performing activities appropriate of his age level?
- How did you find out your child need occupational therapy?
- What do you think is your child's need for occupational therapy?
- What are the feelings of other members of your family about your child's needs?
- Can you describe your situation in relation to the demands of your child's therapy?
- What do you think the therapist is trying to accomplish?
- What are your desired results for your child in relation to his problems or needs?
- How much control do you have of the desired results?
- Can you tell me what are your resources, such as family, friends or other services you can get to help your child.
- Do the therapist's plans and treatment practices for your child correlate with your activities at home?

- If they are similar can you describe how are they similar?
- If they are different can you describe how are they different?
- Does the therapist engages your child in play.?
- Do you know what the therapist is doing when she engages the child in a play activity?
- What do you think of this type of therapy?
- Does the therapist perform painful or disagreeable procedures to your child?
- What do you think of these procedures?
- When the therapist recommends painful procedures to be done at home, do you follow them? Can you explain?
- Can you describe your first encounter with the occupational therapist. What were your impressions.
- Does your child share any feelings regarding occupational therapy and the therapist?
- How do you feel when you have questions or communicate with the occupational therapist?
- Do you think your ethnic background affects your relationship with the therapist? How?
- Age:
- Gender:

- Employed:
- Marital Status:
- Religion:
- Actively involved in religion:

Old Beliefs

- I am going to read you some old beliefs and would you please respond with a YES if you believe it is true, and a NO if you believe it is not true.
- The family is the most important source of moral and economic support one can have in South America.
- The family is the most important source of moral and economic support one can have in the US.
- Hispanic adults take care of their children, and when the times comes, the children will take care of their aging parents.
- The Hispanic mother often assumes the role of "doer" for her children.
- The grandmother matriarch and many female relatives become involved in the care of the children.
- Hispanic children are often spoon-fed and given bottles of sugared beverages at bedtime until they are between 2 and 4 years of age.
- The Hispanic mother continue to dress the child until she is 5 or 6 years of

age.

- The woman in the Hispanic family is the person responsible for communicating and establishing the family's social relationships.
- Hispanic woman believe that a pregnant woman can cause permanent damage to her fetus by making fun of someone with a physical defect or by experiencing a strong emotion.
- Divine punishment, the evil intentions of other, and acts of nature, for example , lunar eclipse, can cause physical or mental disability.
- Hispanic mothers of children with physical or mental disabilities feel very guilty.
- Hispanic mothers of children with physical or mental disabilities overprotect and limit the child's development because of their guilt.

APPENDIX B

RECRUITMENT LETTERS

Dear Professional,

I am looking for Hispanic South American parents who may be interested in participating in a research project. The research project is designed to study cultural characteristics of parents who have children receiving occupational therapy.

Criteria for participation in the research is as follows:

1. The parent must be over 21 years old, and come from South America.
2. The parent must be interested in sharing cultural insights about health beliefs, customs, and information related to the occupational therapy of their child.

If you know of a potential volunteer, please inform him or her of the following:

1. Participation consists of answering questions to and interview in the parents' home or the parents' chosen place, and at their convenience.
2. The questions will focus on present cultural aspects, old beliefs, and occupational therapy.
3. The parent's answers will be taped recorded.
4. All data collected and analyzed will be confidential.

After having explained the above to the parent, please inform him or her that you will give the name and phone number to the researcher. The researcher

will then contact the parent for possible selection. The parent may also contact the researcher at his or her convenience.

Thank you for your assistance in this matter.

Sincerely,

Elsy Arcila-Wilkins, OTS (303) 440-6439

Dear Parent:

I am student currently enrolled at the graduate degree level in the Department of Occupational Therapy at San Jose State University, California. In partial fulfillment of the requirements for the Master of Science Degree, I am completing a thesis entitled "Cultural Characteristics of Hispanic Parents: Issues in Pediatric Occupational Therapy practice."

I intend to increase awareness and add knowledge among health care professionals and educators regarding the cultural characteristics of this population. I also intend to gather data for my case study through interviews with five Hispanic parents of children who have received or are receiving occupational therapy services.

To participate in this study, the parent must be over 21 years of age, and come from Central or South America. Also, the parent must be interested in sharing ideas and opinions about the Hispanic culture, and information related to the occupational therapy of their child. All data collected will be tape recorded and confidential. The interview will take about two hours and can take place in the parent's home or a convenient place, and a convenient time.

To realize this purpose I need your help participating in one interview. If you are interested in volunteering to participate in this research, please contact me

using the envelope I have included or call me.

Thank you for your time and assistance.

Elsy Arcila-Wilkins

(303) 440-6439

Apreciados Padres y Madres:

Yo soy una estudiante asistiendo al programa al nivel master en el Departamento de Terapia Ocupacional en la Universidad Estatal de San Jose, California. Uno de los requisitos para obtener el grado de master en ciencias en dicha profesión es completar una tesis (o libro) que he titulado "Características Culturales de Padres Hispanos: Temas en la Practica de la Terapia Ocupacional".

My proposito es incrementar el conocimiento en los profesionales que proveen servicios en el campo de la salud y la educación acerca de las características culturales de este grupo. Yo me propongo adquirir información para hacer este estudio por medio de entrevistas a cinco padres or madres que tengan hijos o hijas que hayan recibido, o esten recibiendo terapia ocupacional.

Para participar en esta entrevista el padre o madre debe tener más de 21 años de edad y ser Sur Americano o Centro Americano. También, el padre o madre debe estar interesado en compartir ideas y opiniones acerca de la cultura Hispana y también información relacionada con la terapia de su hijo o hija. La información sera grabada y en confidencia, y la entrevista de más o menos dos horas, puede ser en su casa u otro lugar y tiempo conveniente para usted.

Para realizar este propósito necesito su ayuda participando en una entrevista. Si usted esta interesado en participar voluntariamente en esta

entrevista, por favor llámeme o mándeme su teléfono en el sobre que he incluido.

Muchas gracias por su atencion a este favor.

Elsy Arcila-Wilkins

(303) 440-6439

APPENDIX C

SUBJECT CONSENT FORMS

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

College of Applied Sciences and Arts • Department of Occupational Therapy
One Washington Square • San José, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

INFORMED CONSENT

In accordance to our previous conversation, you are invited to participate in a study to share and describe your cultural values, customs and norms, and to state your opinions and impressions about the occupational therapy services your child is receiving. I want to learn more about the Hispanic parents and children in the hope that this information will help occupational therapist and other professionals to provide good quality care.

You have been selected as an interesting participant because you are of Hispanic cultural background, and have being described as willing to share your impressions, opinions, and cultural aspects of your ethnicity.

If you decide to participate, I will like to meet you at your home or at a convenient place and time for both of us. I will be asking questions that relate to both topics, your culture and your child's therapy. With your permission and to facilitate our communication I will be using a tape recorder and will be following a questionnaire. We will spend approximately one hour and a half or two for each interview. If you need more time to communicate all the information solicited, I will make provision for more time.

I will be asking you permission to verify that your child is receiving occupational therapy services with your child's therapist to make the results of my study verifiable, and more believable.

Information that I obtain for this study, and that can be identified with your will be kept confidential, and will be disclose only with your permission. The information that I will be using for the final analysis and report will be regarding the questions answered willfully and without revealing your name or any other names mentioned.

This study will be presented to the Department of Occupational Therapy at San Jose State University. If you decide to participate you are free to discontinue participation at any time without prejudice.

Complaints about the procedures may be presented to Lela Llorens, Ph.D., OTR at (408) 924-3070. For questions or complaints about research subjects rights, or in the event of research related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies and Research at (408) 924-2480.

I cannot and do not guarantee or promise that you will receive any benefits from this study. Other than the time you give to complete the interview, there will be no cost to you. You will not receive payment for your participation.

If you have questions at any time, please ask me directly. If you desire,

you will be given a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that you have decided to participate having read the information provided above.

Signature of Participant_____Date

Signature of Researcher_____Date

AOTA The American Occupational Therapy Association, Inc.

July 12, 1995

Lela A. Llorens, PhD, OTR, FAOTA
San Jose State University
One Washington Square
San Jose, CA 95192-0021

Dear Dr. Llorens:

Permission is hereby granted to reproduce the following materials for the purpose described in your fax of July 6, 1995:

> Figure 1 "The Occupational Performance Frame of Reference" from *A Curriculum Guide for Occupational Therapy Educators.* Please be advised that this product is no longer in publication and is considered out of date.

The request is approved on the conditions:

___ the permission of the author of the material is sought and granted

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Sincerely,

Fran McCarrey

Frances E. McCarrey
Director of Nonperiodical Publications

FEM/eha